An Evaluation of the Role of Conventional and Alternative Discourses on Breast Cancer Research Funding Policies

A Thesis

Submitted to the Faculty

of

Drexel University

by

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In partial fulfillment of the requirements for the degree

Of

Doctor of Philosophy

May 2008

Dedication

I would like to dedicate this study to the women who have come before me; upon whose shoulders I stand and whose work I hope this study can expand.

Acknowledgements

For me, this dissertation and doctoral degree have been a fulfilling journey. Though it has been long, it has not been a solo journey. I have many to acknowledge for their support and encouragement throughout this journey. I begin by thanking God without Whom no journey in life would be possible or successful. Had it not been for my spirituality and faith, I would not have come this far.

I have to thank the staff and faculty at Culture & Communication, Bioscience & Biotechnology and the School of Public Health for all of their help. Academically, my Committee and Supervising Professor served as guides through this journey with their wisdom, encouraging words and support. Dr.Doug Porpora, Dr.Diane Sicotte, Dr.Arthur Frank, and Dr.Lisa Ulmer taught me Sociology, Feminism, Environmental Toxicology, Research Methods, and most of all how to be passionate and still write without bias. I am grateful for the time that each of them took to help me. Dr.Robert Brulle, my Supervising Professor, served as a mentor and coach; he challenged me to develop my own voice and express my intellectual perspective.

In my personal life, I would like to thank my grandparents and parents who raised me to stand up for my beliefs and to never give up. My friends Nancy, Rita, and Lillian for staying the course and keeping me focused to finish. Last but not least, I would like to thank my husband Daryl and my sons Shane and Shon. They pushed me to keep going when I had no energy and understood why I needed to be in front of the computer night after night. They gave me the space, love, encouragement, and the support needed to complete this project and for that I will never be able to repay them.

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Abstract

An Evaluation of the Role of Conventional and Alternative Discourses on Breast Cancer Research Funding Policies

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Breast cancer continues to be one of the leading causes of morbidity and mortality for women in the United States. It is estimated that every three minutes a woman is diagnosed with breast cancer and every twelve minutes a woman dies from this disease. Research has identified three potential causes for breast cancer: genetics, lifestyle choices and the environment. Genetics and lifestyle choices contribute to less than 30% of breast cancer cases; the remaining 70% of all cases can be linked to the environment and environmental carcinogens. Environmental carcinogens can be found in cosmetics, household cleaning materials, and as by products of pollution, such as PCBs and organochlorides. Elimination of environmental carcinogens would lead to prevention. Despite this fact, research funding policies tend to neglect the role of environmental carcinogens which have been linked to breast cancer and instead fund research for new screening and treatment methods.

In order to determine how and why research funding policies for breast cancer are formulated and if in fact these policies systematically exclude funding for the role of environmental carcinogens, a thorough analysis of the research funding policies had to be conducted. This study applied theoretical arguments from sociology, elaborated on policy theories and utilized the Advocacy Coalition Framework (ACF) and Congressional hearings to evaluate how and why research funding priorities for breast cancer are determined. The results of this study revealed that: the discursive coalitions advocating

for research into the environmental causes of breast cancer are marginalized during the Congressional hearings; due to this marginalization, research funding is limited for the environmental coalition; and that the majority of hearing testimony is impacted by the economic interests of the presenter. Since the environmental coalition does not have equal participation during the Congressional hearing process, it also does not receive equal funding for research activities.

CHAPTER 1: INTRODUCTION

Overview

Breast cancer continues to be one of the leading causes of morbidity and mortality for women in the United States and around the world (Evans, 2006 p2; Epstein & Steinmen, 1997 pp.2-10). It is estimated that every three minutes a woman is diagnosed with breast cancer and every twelve minutes a woman dies from this disease in the United States (McCormick, 2003pp.545-549). Since the 1940's, well over a million women have been diagnosed with breast cancer around the world (Evans, 2006). In the United States, breast cancer is the most commonly diagnosed cancer among women and approximately 40,000 women lose their lives to this disease annually (Evans, 2006; CDC, 2006). In fact, the incident rate for breast cancer has risen dramatically over the past four decades (Epstein & Steinmen, 1997; NCI, 2006; ACS, 2006).

In the United States, well over a billion dollars have been spent during the past four decades for breast cancer research (NCI, 2006; Epstein & Steinmen, 1997). This research has identified three potential causes or risk factors which can be associated with the development of breast cancer: genetics, individual lifestyle choices, and the environment. (NCI, 2006; Evans, 2006; Epstein & Steinmen, 1997). The literature shows that genetics and lifestyle choices contribute to less than 30% of breast cancer cases; while the remaining 70% of all cases can be linked to environmental carcinogens (NCI Budget Portfolio, 2005; Breast Cancer Action, 2006). These carcinogens can be present in cosmetics, household cleaning materials, and as by products of pollution, such as PCBs and Organochlorides (Epstein & Steinmen, 1997:2-10). More research into the role of these environmental carcinogens as risk factors for breast cancer and elimination

of these environmental carcinogens could lead to prevention and reduce the incidence of breast cancer (Evans, 2006: 4-10; Epstein & Steinmen, 1997:2-10).

Statement of the Problem

The federal agency responsible for determining most of the research activists and influencing research policies for cancer in the United States is the National Cancer Institute (NCI). NCI's research priorities fund research activities which are geared towards genetics, lifestyle choice, and the development and implementation of new screening methods and medical treatments. Research into the role of environmental carcinogens receives less then 5 % of the available research funding, despite the fact that 70% of breast cancer cases can be linked to environmental carcinogens (NCI Budget Portfolio, 2005; Breast Cancer Action, 2006).

In addition to research funds from NCI, over the past decade breast cancer has become one of the most publicized forms of cancer. The "pink ribbon" and the annual "Race for the Cure" charity event have become well known symbols for this disease (Kolker, 2004:820-844). Many breast cancer NGOs (Non- Governmental Organizations) have been formed and private fundraising activities such as the "Race for the Cure" have been initiated to raise awareness and funding for research (Epstein & Steinmen, 1997; Moss, 2002). With increased public and private research dollars available, the incidence rates for breast cancer should have declined (CDC, 2006).

However, the incidence rates for breast cancer have actually doubled from 1 in 14 women in the 1960s to 1 in 7 women today (Evans, 2006: 3-5). This higher rate may be

attributed to increased screening by physical examination and mammography; however, a closer look at the population statistics about the incidence rate reveals that screening does not explain the higher rates (Brody, 2005; NCI, 2006). The high incidence rates of breast cancer coupled with the amount of research funding available from both public and private sources, raises questions about what research activities are funded and how and why research funding policies are determined.

A review of the literature suggests that there seem to be two main discourses which attempt to explain how and why these research policies are determined. The first discourse stems from the NCI and American Cancer Society (ACS). This discourse explains that the research funding policies need to focus research activities around the first two risk factors, genetics and lifestyle choices, based on the following reasons:

- the increase in breast cancer can be attributed to women living longer and improved screening methods;
- medical treatments save lives and prevention techniques are not really available;
- it is difficult to impact the lifestyle choices of women;
- and it is difficult to study the effects of the environment and conclusively pinpoint how the environmental carcinogens cause breast cancer (NCI, 2006; ACS, 2006).

The second discourse disagrees with these reasons and explains that the research funding policies systematically exclude funding for the role of environmental carcinogens because of the following reasons:

- the "ruling class" of agencies (the "Cancer Establishment" and "Cancer Industry") which determine the research priorities are led by individuals with conflicts of interest;
- these conflicts of interest include companies which sponsor Breast Cancer Awareness month and who also own the chemical companies which produce herbicides that are linked to breast cancer incidence (Epstein & Steinmen, 1997).
- powerful corporate actors, such as the pharmaceutical companies, promote research funding policies for medical treatment and exclude funding for the environmental causes because of profit;
- the existing research funding policies for new screening and medical treatments are more profitable than mitigation of environmental carcinogens which may lead to prevention (Moss, 2002).

In order to determine how and why research funding policies for breast cancer are formulated and if in fact these policies systematically exclude funding for the role of environmental carcinogens, a thorough analysis of the research funding policies had to be conducted. This study applied theoretical arguments from sociology, elaborated on policy theories and utilized the Advocacy Coalition Framework (ACF) to determine how and why research funding priorities for breast cancer are determined.

The Advocacy Coalition Framework (ACF) provided a mechanism for reviewing how competing advocacy coalitions, changes in external subsystems, and a stable system of parameters impact policies (Sabatier, 1993). The competing advocacy coalitions are the actors from public and private institutions at varying levels of agencies and

government who share belief systems and work to impact the policies to match these beliefs. The external subsystems are the economic and other systems which impact these coalitions in their quest to influence the policy process. The stable system of parameters are the rules or the social structures that set the constraints for the policy process (Sabatier, 1993).

The ACF explains that the policy process involves competition between the different stakeholders or advocacy coalitions to establish and maintain the elements of public policy; these coalitions unite based on their core beliefs and drive the policy process. The ACF defines an advocacy coalition as a group of "actors" in a policy subsystem from a variety of institutions, who share core ideas or beliefs on a particular policy issue and they coordinate their actions to form policies based on the core ideas or beliefs (Weible, 2005). These dominant coalitions are not stagnant; they change over time and so do the external subsystems and policies (Sabatier, 1993).

The ACF has been used in the analysis of air pollution and the formation of air quality policies where there were and are strong advocacy coalitions, and market systems in place to drive the policies in different directions. In the case of research funding policies for breast cancer the two main discourses described earlier which can be linked to six advocacy coalitions consisting of various actors or agencies, who have certain core beliefs about what research should be funded. These six advocacy coalitions for research funding are: genetics, lifestyle choices, screening methods, medical treatment, environmental carcinogens and prevention. The conventional discourse emphasizes the first four coalitions and the alternative discourse emphasizes the last two. Also, there are external subsystems such as the economic conditions and incident and mortality rates for

the disease; and there are the relative stable parameters, such as the Cancer Act and the availability of resources. All of these components combine during Congressional hearings to drive the policy process and form research funding policies, which determine federal appropriations and the national budget.

Congressional hearings provide a written record of the discussions about issues, the actors and agencies involved in these discussions and how they combine to form or change policies. These hearings provide a narrative text of the policy process discussion and the key actors who were included or excluded in the discussion to impact the creation or change of a policy (Lounbury, 2003:71-104). By conducting content analysis on Congressional hearings and applying the ACF, it was hoped that reasons for how and why the policies for research funding are decided will be determined.

Rationale for the Study

This proposed study will advance the understanding of how and why breast cancer research funding policies include or exclude funding for certain risk factors over others. The existing literature points to multiple carcinogens in the environment, as well as genetics and life style choices as triggers for causing breast cancer (Evans, 2006; Epstein & Steinmen, 1997:2-10). Despite the existence of this literature, there seems to be a disparity in research funding policies; this dissertation aimed to help determine how the research funds are being spent and why certain causes receive more research funding and other causes are not funded.

The Delimitations

This study proposed to provide an accurate picture of the policy process for breast cancer research funding policies and how and why certain causes receive funding over other causes. Two limitations were identified for this study. Actual Congressional hearings which encompass agents or actors can be complicated and often very dynamic. Thus, this study is limited by the narrative text provided as a written record of the hearings, which does not include the actual visual presentations that may have been provided by these agents or actors. The study was also limited by the reliance on US Government Printing Office to provide an accurate, written record of the hearings.

Assumptions

For the purposes of this study, the following assumptions were made: the Congressional hearings used in the study were inclusive of breast cancer policy hearings; the ACF served as a good framework for this type of analysis; and that the variables chosen for study will be adequate.

Definition of Terms

Listed below are the terms and definitions that will be utilized to represent the advocacy coalitions for this study:

Genetics: Defined as the study of heredity; for the purposes of this study, refers to the evidence that there are "breast cancer genes" which seem to be responsible for contributing to breast cancer: the BRCA1 and the BRCA2 genes (Steingraber, 2000 & Epstein 2003).

Lifestyle Choices: defined as smoking, alcohol consumption, diet, exercise, reproductive behavior, and driven by cultural beliefs and social status (Steingraber, 2000 & Epstein 2003).

Screening Methods: Defined as tests and exams used to find breast cancer in people who may not have any symptoms; the three methods are breast self-exam, clinical breast exam, and mammograms (ACS, 2007).

Medical Treatments: Defined as medical intervention for a disease; for breast cancer, the treatment options can involve removal of the tumor, removal of the breast, chemotherapy, radiotherapy, and other medications (ACS, 2007).

Environmental Carcinogens: the environment, environmental pollutants and carcinogens that are considered as triggers for breast cancer causation (Epstein, 2003, 2005). Chemical pollutants produced by industrialization and are not the only environmental carcinogens, radiation and everyday items, such as cosmetics, pesticides, and household cleaning materials may also cause breast cancer (Brody, 2005).

Prevention: though usually associated with early detection and education about lifestyle choices; for the purpose of this study, prevention will be defined in relation to minimizing exposure to environmental carcinogens (Steingraber, 2000 & Epstein 2003).

CHAPTER 2: LITERATURE REVIEW

Overview

Chapter one introduced information about the breast cancer epidemic and the three risk factors associated with this disease. The chapter also provided the overall statement of the problem and the aims of this study, to identify how and why breast cancer research funding policies include and exclude funding for certain risk factors. This chapter will provide a brief history of this disease; details about the risk factors; the two main discourses and the associated six advocacy coalitions that explain how and why these research policies are determined; the theoretical framework; and a summary of the major findings and gaps.

History & Etiology

Human beings have been trying to understand and battle cancer for centuries. The earliest evidence of human cancer dates back to 460-370 B.C showing damage to organs and bones from malignant tumors (Diamandopoulus,1996:1595-1602 & Gallucci, 1985:67-71). From the beginning, humans have tried to understand what cancer was and how it developed. The notion of cells in the human body forming tumors and attacking the body that they dwell in has perplexed society for centuries (Diamandopoulus,1996:1595-1602).

Cancer as defined by the Stedman's Medical dictionary is the "various types of malignant neoplasms, most of which invade the surrounding tissues, may metastasize to several sites and invade surrounding tissues… can cause death to the patient…"

(Stedman's, p276). The actual word cancer comes from the Latin word for crab. Basically, cancer is the result of normal cells producing abnormal daughter cells during cell division. These abnormal daughter cells attack nearby tissue and organs and can migrate through the body via the bloodstream and lymphatic system to spread the cancer. Besides being abnormal, cancer cells reproduce more rapidly than normal cells and as time goes on these abnormal cells form malignant tumors or cancer (National Cancer Institute, 2000).

In the case of breast cancer, the disease begins when cells in the breast tissue called lobes and ducts begin to multiply abnormally and form tumors. The breast consists of glands called lobules which produce breast milk, small tubes called ducts that connect the lobules to the nipple, both fatty and connective tissue, blood vessels, and lymph vessels. Lymph vessels are similar to veins that carry lymph fluid which contains immune cells and other fluids. These vessels are distinct of the tissue that forms the lymph nodes. These nodes extend into the arm pit area and are called axillary nodes (ACS, 2006).

Most lumps in the breast tend to be benign breast tumors which do not spread throughout the body. Simple removal of the benign tumor is required. If however, the tumor is malignant it can spread locally or the cancer can spread through the lymph nodes and the bloodstream to the rest of the body (Anatomy of the Breast, 2003). A graphical description of how and where breast cancer develops is provided on the next page (ACS, 2006).

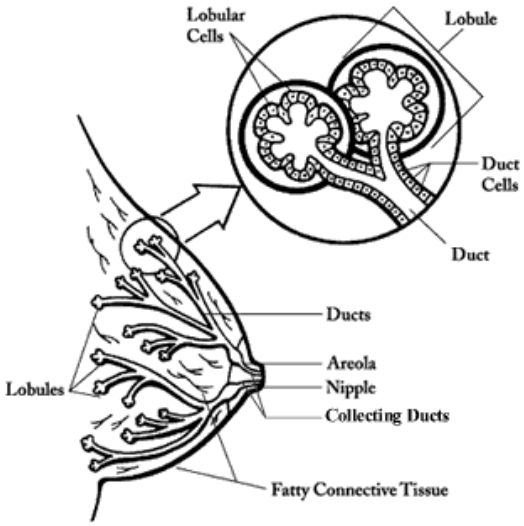


Figure P-1: Diagram of Breast: "A woman's breast is made up of glands that make breast milk (lobules), ducts (small tubes that carry milk from the lobules to the nipple), fatty and connective tissue, blood vessels, and lymph (pronounced **limf**) vessels. Most breast cancers begin in the cells that line the ducts (ductal cancer), some begin in the lobules (lobular cancer), and the rest in other tissues. Lymph vessels are like veins, except that they carry lymph fluid instead of blood. Lymph is a clear fluid that contains immune system cells and waste products. Most lymph vessels lead to small, bean-shaped collections of tissue called lymph nodes. Most lymph vessels of the breast lead to lymph nodes under the arm. These are called axillary (**ax**-uh-lair-ee) nodes. If breast cancer cells reach the underarm lymph nodes and continue to grow, they cause the nodes to swell. Once cancer cells have reached these nodes they are more likely to spread to other organs of the body as well." (ACS, 2006: http://www.cancer.org/docroot/CRI/content).

The history of the various types of cancer varies based on incidence of that particular type and the percentage of population affected. The first documented case of breast cancer in the world can be traced back to 1600 BC (Diamandopoulus,1996:1595-1602 & Gallucci, 1985:67-71). In the United States breast cancer and formal treatment can be traced back to 1890, when the American surgeon William Halstead developed the radical mastectomy (Plotkin, 1996: 53-82). This surgical procedure involved a complete removal of the tumor and everything around it including the chest-wall muscles and lymph nodes. The goal of this surgical procedure was to remove the tumor to eliminate the spread of

the cancer. Often, however, this procedure left women horribly disfigured and sometimes considered to be outcasts of society (Plotkin, 1996: 53-82).

This procedure of surgically removing the tumor made the assumption that the cancer spread slowly and steadily from one site to the rest of the body and that removal of the tumor was sufficient (Plotkin, 1996: 53-82). It did not explain how and why the cancer reoccurred or spread to other areas of the body. It was not until surgeons and radiologists began working together to better understand how breast cancer spread, with the hope that this cancer could be controlled, that the concept of early detection through X-rays or what is now known as mammography was conceived (Love & Barsky, 1996:171-175).

In the early 1930's this idea of trying to control the breast cancer through early detection and the negative implications of the radical mastectomy lead the medical community to develop medical treatments that were less invasive and screening methods for breast cancer with the hope that the disease would be found before it spread to other organ systems in the body (Love & Barsky, 1996:171-175). Self breast exams and mammograms were developed later as a result of this earlier work (ACS, 2004).

Also during this time, the United States government and its political leaders began to realize the potential catastrophic effects of cancer on the American people and passed the National Cancer Act creating the National Cancer Institute (NCI). This new government agency complimented the American Cancer Society (ASC), an NGO which was originally formed in 1913 in New York City (Glazer, 1997:1-40). These agencies and the

medical community began significant research activities to find treatments and a cure for cancer in the 1960's (ACS, 2004).

The NCI was empowered further through amendments to the National Cancer Act, and the ACS was empowered through increased publicity and funding. The medical community also continued the quest for better treatment options including chemotherapy, radiation and tumor or organ removal as the last resort. Funding for research into new medical treatments and finding a cure for breast cancer increased over time (Glazer, 1997:1-40). As the rates of breast cancer continued to rise, the Breast Cancer Act of 1990 and new NGOs were formed and commissioned to raise awareness and private funding to conduct research for a cure (McCormick, 2003:545-576).

As these NGOs spent their time emphasizing the need for treatment and cure for breast cancer, women began to organize around defining the causes of breast cancer. One of these women was 68-year-old Charlotte Haley. Ms. Haley had begun making peach ribbons in her home and distributing these ribbons to raise awareness because her daughter, sister and grandmother all had breast cancer. She realized the need for research activities which focused specifically on determining a cause for this disease and the possible prevention activities necessary to control this disease. She distributed thousands of peach ribbons in her home town at stores with cards that read: "The National Cancer Institute's annual budget is $1.8 billion, only 5 percent goes to cancer prevention through the elimination of environmental carcinogens. Help us wake up our legislators and America by wearing this ribbon." (Breast Cancer Action, 2006).

At the same time that she was successfully raising awareness with her ribbon, a need for a national logo for breast cancer had surfaced. The information about Ms.Hailey's ribbons reached the executives from Estée Lauder and *Self* magazine and they stepped in and asked her if they could use her ribbon. Even though Ms. Haley refused, these two corporations consulted their attorneys and came up with the pink ribbon. Of course, Haley's ribbon was no longer valuable and the pink ribbon became the commercialized symbol for breast cancer (Breast Cancer Action, 2000).

Causes & Risk Factors

Though the exact causes of breast cancer have not yet been determined, the majority of literature and research point to three potential causes: genetics, individual lifestyle choices, and the environment (Steingraber, 2000; Epstein, 2003; Davis, 2002:159-192). There is a body of literature to support the need for additional research funding to conduct research activities which target each of these three causes (NCI, 2006). A brief explanation of each of these causes will now be provided.

Genetics

Breast cancer research activities have collected data about the role of DNA and genetic mutations that are passed down from one generation to the next that may lead to breast cancer in the offspring (NCI, 1995). There is evidence that there are "breast cancer genes" which seem to be responsible for causing breast cancer: the BRCA1 and the BRCA2 genes. These genes are mutated from normal cells and are inherited by offspring and can potentially cause breast cancer in the individual who inherits the mutated genes (Anatomy of the Breast, 2003). One of the medical treatments that can

help women who have the BRCA1 mutation is to have their ovaries surgically removed before age 40. This procedure seems to reduce the risk of breast cancer (ACS, 2006). Another medical treatment involves the drug tamoxifen. Though the research is still ongoing, some studies have shown that women who have a higher risk for breast cancer may not get the disease if they take this medication. Raloxifene, another medical drug that is being tested to see if it reduces breast cancer risk (ACS, 2006)

Though the BRCA 1 and BRCA2 genes have been identified as potential triggers for breast cancer, the literature suggests that more research needs to be conducted to establish a conclusive link (Brody, 2005). There is only a weak link between heredity and breast cancer and there is evidence that the majority of breast cancer occurs without specific genetic causes (Vogelstein, 1995). Only 5 to 10 percent of cases can be linked to genetics, the remaining 90 to 95 percent of breast cancer cases do not have a conclusive hereditary connection (Colditz, 1993: 338-343).

Research has suggested that the breast cancer genes may be a result of genetic mutations which may have been caused by exposures to environmental carcinogens. DNA mutations are generally caused by exposure to certain environmental carcinogens; this mutated DNA can be passed down from parent to child causing the child to become more sensitive to certain environmental carcinogens (Holzman, 1996:951). For example, the mutated DNA that is passed down to the child in the case of 5 to 10 percent of heredity related breast cancer cases may be responsible for the abnormal cell division causing tumor formation in the breast (Steingraber, 2000). The exposure to environmental carcinogens, which may produce mutated DNA and “cancer genes” can be

passed down to the child from parent (Steingraber, 2000). Endocrine disruptors are one example of how exposure to environmental carcinogens can cause genetic defects (Solomon, 2002:147-162). Endocrine disruptors are the hazardous chemicals that work by binding to or blocking hormone receptors and can lead to genetic mutations (Steingraber, 2000). Understanding the effects of exposures to environmental carcinogens and endocrine disruptors may assist in mitigating and eliminating the carcinogens present in the environment and prevent breast cancer; not much can be done to change the current genetic material that an individual inherited (Steingraber, 2000).

Lifestyle Choices

Research activities also focus on the impacts of individual lifestyle choices and how these choices may cause an individual to acquire breast cancer. Many public health education campaigns have been developed to promote healthier lifestyle choices (Evans, 2006). Both the NCI and the ACS spend a large portion of their research funding on educating and promoting "better lifestyle choices" (ACS, 2006; NCI, 2006). There are a multitude of media messages and health education literature which associate individual lifestyle choices to breast cancer.

Lifestyle choices encompass: smoking, alcohol consumption, diet, exercise, reproductive behavior, and cultural beliefs (Steingraber, 2000; Epstein 2003; Knope-Newman, 2004:845-874; ACS 2006; NCI, 2006). Of these choices, smoking has been linked to lung cancer and alcohol consumption has been shown to increase the risk of certain cancers, such as liver cancer (Anatomy of the Breast, 2003; Epstein & Steinman, 1997:2-10, ACS 2006; NCI, 2006).

There is a great deal of research that points to a diet high in fat as one of the causes of breast cancer. Studies have been conducted to show that diets high in animal fats and low in fiber can lead to higher rates of breast cancer (Wallis, 1991). The high fat diet seems to coincide with the lack of exercise and research has shown that exercise can actually reduce the risk of acquiring breast cancer (Anatomy of the Breast, 2003, Epstein & Steinman, 1997). Though the evidence is weakly linked to actually impacting breast cancer rates, generally speaking, individuals who engage in regular exercise tend to have a better diet and are less likely to have bad habits such as smoking (Steingraber, 2000; Moss, 2002). Another factor that may link diet and breast cancer involves food production. The majority of food produced tends to have additives, pesticide residues, and endocrine disruptors which have been linked to the development of cancer (Brody, 2005). Also, pollution of the water supply and air quality can have an impact (Steingraber, 2000).

Female reproductive factors and behaviors are also considered as major lifestyle choices that influence the risk of developing breast cancer (NCI, 2006; ACS, 2006; Anatomy of the Breast, 2003). The two main reproductive factors and three behaviors that attribute to increased breast cancer risk are: age of first menstrual period, age at the onset of menopause, using the birth control pill, age of first full-term pregnancy, and breastfeeding (Bernstein, 2002).

The literature suggests that a woman who has her period before the age of 12 or a woman who begins menopause at or after age 55 is more likely to have breast cancer (Epstein & Steinman, 1997). This is because of increased exposure to estrogen.

Estrogen is the hormone released when menstruation begins. Menstruation at an early age increases the length of exposure to estrogen. Later onset of menopause also increases the length of time a woman is exposed to estrogen, since estrogen is associated with both menstruation and menopause (Epstein & Steinman, 1997). Though this research does not provide conclusive data about the role of estrogen as a carcinogen or how to control estrogen levels, it is considered to be a risk factor for breast cancer (Bernstein, 2002; Susan G. Komen Foundation, 2006). The other interesting issue with these two lifestyle risks is that women do not have control over the onset of their periods or onset of menopause, and estrogen is a naturally occurring hormone within the female body; how it becomes a carcinogen requires additional research (Steingraber, 2000). Other exposures to estrogen may come from using the birth control pills which contain varying concentrations of estrogen (Epstein & Steinman, 1997). The pill generally contains estrogen and progesterone, and, as mentioned earlier, estrogen is a known carcinogen for breast cancer (Epstein, 2003).

The age of first full-term pregnancy is also a lifestyle choice that is implicated as a risk factor for breast cancer. Research suggests that having a child prior to age 30 seems to have a "protective effect" against breast cancer (NCI, 2006). Though the mechanism of how this protective effect works is still unknown, it is considered one of the lifestyle choices that can protect a woman against breast cancer (Sturgeon, 1995).

Breast feeding is also a lifestyle choice that is considered as a risk factor for breast cancer (Epstein & Steinman, 1997). There is research underway to determine whether or not breastfeeding has a protective effect against breast cancer. The current

thinking is that breast feeding for more than a year will have a protective effect and less than a year will not (Newcomb, 1997; Bernier M, 2000:374-386). The other issue that complicates breast feeding and the risk for breast cancer involves the chemical body burden of the mother and how much of the chemicals she will pass to the child through the breast milk (Epstein & Steinman, 1997).

Though cultural beliefs and social status are not usually considered lifestyle choices, both of them can impact an individual's ability to make lifestyle choices. There are many health behavior models which emphasize the role of cultural beliefs on the perception of health and the cues to action that will lead to behavior change and even seeking medical care (Epstein, 2003). One of which is the Health Belief Model (HBM). The key concepts of the HBM are: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Glanz, 1997). The HBM emphasizes the role of cultural beliefs on perceived susceptibility of breast cancer as a potential reason for minority women not seeking medical care for breast cancer. One of the current prevention strategies for breast cancer is "early detection" through screening. Screening or early detection can be accomplished by a self exam of the breast, medical exam, or a mammogram (Kopans DB. 2000, MMWR, 1997 & Iezzoni LI, 2001). Based on the HBM, a woman may be less likely to engage in "early detection" activities, if her cultural beliefs deemphasize such activities.

The role of cultural beliefs and access to care may explain why breast cancer statistics show that though Caucasian woman have higher incidence rates of breast cancer, African-American and other minority women are more likely to die from breast cancer (NCI; ACS; and Epstein, 2003). Given the fact that cultural beliefs significantly

influence health behavior and cues to attaining medical care and that screening is a key to preventing and controlling breast cancer, the reasons for higher rates of Caucasian women getting breast cancer and more minority women dying from breast cancer may be linked to cultural beliefs (ACS, 2000 & CDC, 2004). Caucasian women are more likely to receive routine medical care, unlike their minority counterparts who may be less likely to seek medical care, due to access to health care issues or beliefs associated with their culture (Epstein, 2003). These issues may explain why minority women are more likely to die from breast cancer because when the cancer is finally detected, it is often too late for medical intervention (Breast Cancer Action, 2006). Listed below are some graphs that show how the incidence rate for breast cancer has risen and the variation in the incidence and mortality rates for all women by race (NCI, 2005).

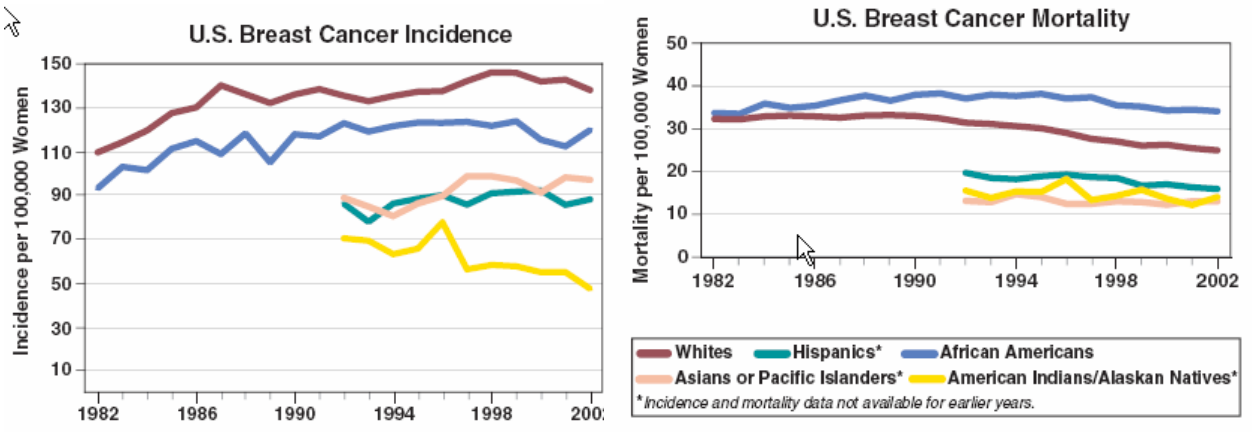


Figure P-2: Incidence and Mortality Rates: for Breast Cancer National Cancer Institute "A Snapshot of Breast Cancer".

Coupled with cultural beliefs is social status. Social status can be defined as an individual's race, gender, level of education, or Socioeconomic level; therefore social status tends to impact an individual's cues to action for medical care (Glanz,1997; Epstein 2003; Moss 2002). An individual's social status plays a big role on the amount of exposure that she or he has to a hazardous environment (Bryant, 1995; Hofrichter, 2000). Low Socioeconomic Status, being a minority and having a low educational level can impact an individual's ability to obtain medical care and can play a strong role in lifestyle choices. For example, minority women are less likely to get a mammogram because they are less likely to be able to afford it (Epstein, 2003). Also, these women may be more likely to live in polluted environments which contain the carcinogens and endocrine disruptors that cause breast cancer.

Environmental Justice (EJ) literature has shown that an individual's proximity to environmental carcinogens is based on social status (Bryant, 1995; Hofricter, 2000). The Environmental Protection Agency (EPA) defines EJ as: "the fair treatment for people of all races, cultures, and incomes, regarding the development of environmental laws, regulations, and policies" (EPA, 2005). Another definition is "the pursuit of equal justice and equal protection under the law for all environmental statutes and regulations without discrimination based on race, ethnicity, and/or socioeconomic status. The EJ literature has shown evidence that minorities and people with low Socioeconomic Status are more likely to live near environmental hazards, some of which may contain the environmental carcinogens that can be linked to causing breast cancer (Bryant, 1995; Hofricter, 2000).

The Health Behavior Model coupled with the environmental justice literature suggests that the role of an individual's lifestyle choices may be less responsible for causing breast cancer; instead it may be the social processes which produce the environmental carcinogens. Based on the information about lifestyle choices, very few, if any, are really at the discretion of the individual. Most of the lifestyle choices are connected with the individual's surrounding environment.

The Environment

The role of exposure to environmental pollutants and carcinogens leading to negative health impacts have been studied since the 1800s and conclusive evidence of adverse health effects from carcinogenic chemicals have been reported since 1940 (Tomatis, 2004). The evidence about the dangers of pesticides to the environment and human health reached the public with Rachel Carson's book *Silent Spring*. Later Sandra

Steingraber's *The Social Production of Cancer: A Walk up Stream* provided additional evidence to support the link between environmental carcinogens and cancer (Stiengraber, 2000). The Long Island and Cape Cod Studies, two research projects conducted in the late 90's, further strengthened the evidence for the connection between environmental pollutants and breast cancer (Brody, 2005 & Glazer, 2005). Chemicals produced by industrialization and a technocratic way of life are not the only environmental carcinogens. Radiation and everyday items, such as household cleaners and cosmetics, are all contributors of breast cancer (Brody, 2005). Some of these items contain chemicals that are endocrine disruptors (Solomen, 2002).

Endocrine disruptors have been studied since the 1930s in laboratory animals. These animal experiments revealed that certain industrial chemicals impacted not only the animal exposed, but also the offspring (Solomon, 2002). In the 50s a similar impact was noted from pesticides and later written about by Rachel Carson in the book *Silent Spring*. Carson alluded to the endocrine disruptor process and the impact on the environment and human health. This book sparked immense negative feedback and attacks on Carson from the pesticide industry and the government (Lear, 1997).

Endocrine disruptors are the hazardous chemicals that work by binding to or blocking hormone receptors (Solomen, 2002). This binding and/or blocking of hormone receptors leads to dysfunctional transcriptions of genes and the production of genetic mutations (Cooper, 1997: 159-166). These mutations are often passed down to the offspring and can eventually lead to the production of abnormal cells and cancer (Solomon, 2002). The endocrine disruptors that impact breast cancer are in a special category called the Mammary Endocrine Disruptors (Brody, 2005). Mammary endocrine

disruptors seem to play a key role in the development of breast cancer cells and genetic mutations. The majority of these endocrine disruptors can be found in household products used by women, including: beauty products, home furnishings, detergents, and plastics (Brody, 2005).

Environmental carcinogens and the role of the environment have surfaced as contributing factors for the other two causes of breast cancer: genetics and lifestyle choices. In the case of genetics, environmental carcinogens have been shown to be a potential cause for DNA mutations. In the case of lifestyle choices, environmental carcinogens can impact diet and reproductive health. All of these issues combined, lead to questions about the actual role of the environment and environmental carcinogens as a cause of breast cancer, and how much research is being conducted to identify and mitigate these environmental carcinogens.

Figures P-3 shows incidence rates for breast cancer by states and Figure P-4 shows the states or areas that have active sites that are on the Super Fund and the National Priorities Lists (NPL) (EPA, 2006). To date there has been little to no research that correlates the rates of breast cancer incidence with where an individual lives and the proximity of this location to sites containing environmental carcinogens. If these maps were superimposed, the states which have many Superfund and NPL Sites are also the same states that have the higher rates of breast cancer incidence. The east coast seems to have higher rates of breast cancer and environmentally hazardous sites (Evans, 2006). Though simply superimposing the maps would not be evidence enough, research funding policies have yet to conduct research on the correlation between breast cancer rates and proximity to these environmentally hazardous sites (NCI and ACS, 2005).

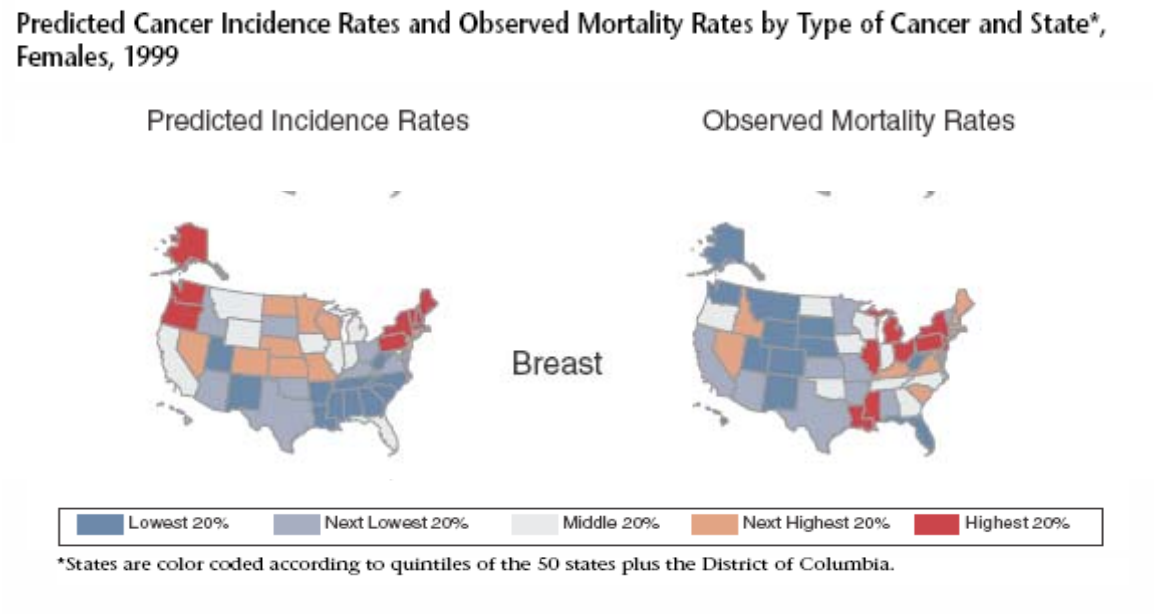


Figure P-3: Incidence and Mortality Rates by State: National Cancer Institute "A Snapshot of Breast Cancer".

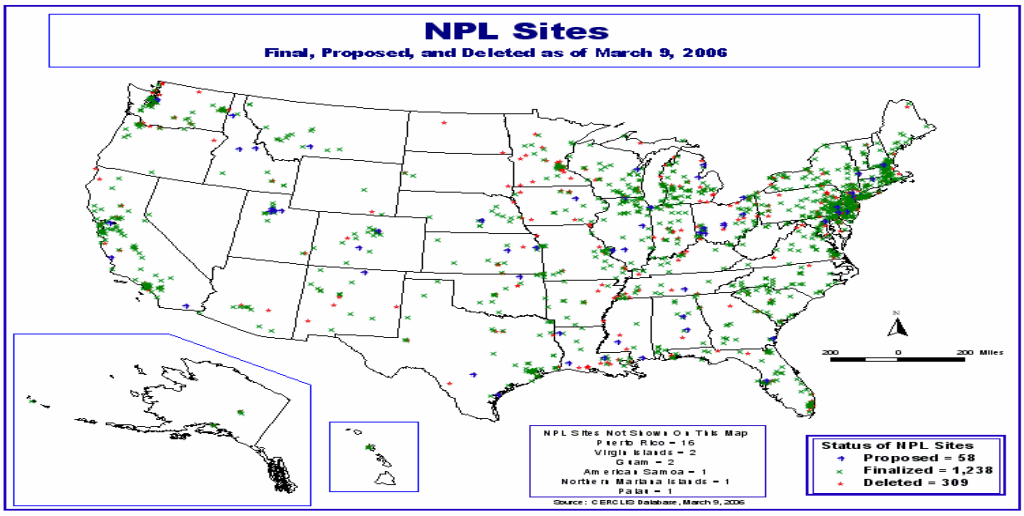


Figure P-4 NPL Sites by State: for the United States based on current EPA data**.**

The role of the environment as a causative agent for breast cancer is further supported by reports such as *State of the Evidence: What is the Connection Between the Environment and Breast Cancer.* This type of report has been published annually for a number of years and it demonstrates that there is substantial scientific evidence which links exposure to radiation and synthetic chemicals to an increased risk of breast cancer. The report provides findings from more than 350 experimental, epidemiologic and ecological studies and the need to act on the evidence and reduce human exposure to environmental carcinogens such as radiation and synthetic chemicals. A multitude of environmental chemicals which have been linked to breast cancer occurrence are documented in this report, the most common of which are listed below (Evans, 2006):

- Bisphenol-A (BPA): a chemical used to make polycarbonate plastic;
- Diethylstillbestrol (DES): a drug that has now been banned for decades but was prescribed to women to prevent miscarriages;
- Polyvinyl Chloride (PVC): found in plastics used for food packaging, medical equipment, appliances, cars, toys, and even credit cards;
- Dieldrin: a pesticide that has been banned, but is still persistent in the environment from where it was used;
- Aromatic Amines: which are a class of chemicals found in the air, water, plastics, diesel exhaust, tobacco smoke, and grilled meats. O-toluidine is an aromatic amine that has been linked to mammary tumors in rodents;
- 1,3-Butadiene: a carcinogen that is found in the air and has been on the Environmental Protection Agency's (EPA) list of know human carcinogen's list, yet it is still emitted into the air;

- Polycyclic Aromatic Hydrocarbons (PAHs): found in fumes, cigarette smoke, and are produced during grilling and other processes;
- DDT and PCB's: though both have been banned from use in the United States for decades, they are still present in the environment and can be found in fatty tissue and breast milk;
- Dioxins: chemicals are highly prevalent in the environment and can be found in humans; (Evans, 2006).

The list above represents just a few of the chemicals that are known carcinogens which may cause breast cancer (Evans, 2006). The impact of environmental carcinogens on health is also emphasized in books, such as Joseph LaDou's *Occupational and Environmental Medicine,* a textbook used in medical and environmental science curriculums (LaDou, 1997). However, the information about role of the environment on health outlined in this and other textbooks is not usually public knowledge (Steingraber, 2000).

Devra Davis, in her book *When Smoke Ran Like Water*, provides a historical narrative about the role of the environment on the occurrence of breast cancer in a chapter entitled: "The New Sisterhood of Breast Cancer". This chapter tells the story of Bella Abzug and how she convened a public hearing in New York City to find out why research funding policies remain focused on treatment, when no new treatments have been developed in over two decades (Davis, 2002: 181). Davis touches on the role of patriarchy as she shares how there has been a change in the discourse of breast cancer and how the disease went from being whispered about to breast cancer becoming a national agenda item (Davis, 2002: 181).

Though it is true that breast cancer has become a national agenda item, research funding policies still tend to focus on genetics and lifestyle choices through new medical treatments and screening methods (Davis, 2002:159-192). Over 85,000 synthetic chemicals are in use today to make everything from lipstick to furniture to the plastics in water bottles and pesticides (Evans, 2006). Still less than 5% of available funding is dedicated towards research activities that evaluate the role of these carcinogens on breast cancer (NCI, 2006).

Ionizing radiation can also be attributed as a cause for breast cancer and genome instability (Evans, 2006; 20-45). It is a form of radiation that contains enough energy to cause cancer and this form of radiation is utilized in mammography, X-rays, and other areas of the environment (Evans, 2006). Although it has been suggested, that there are "safe doses" of radiation, there is no conclusive research evidence to prove that radiation at any level is safe (Evans, 2006). There seems a great deal of literature that points to the environment as a cause for breast cancer and the need for funding research activities which include the role of environmental carcinogens; however, most of this literature does not ask why current research funding policies do not emphasize such research activities.

Current Research Funding Priorities

As mentioned in the History and Etiology section of this chapter, the research funding policies for breast cancer are established by the National Cancer Institute (NCI) and the American Cancer Society (ACS). These agencies work together to raise awareness about breast cancer and provide reports and feedback to members of Congress

about what is currently being researched and what should be researched. The NCI and ACS make suggestions for what items should receive appropriations from Congress. Congress conducts appropriation hearings where testimony is given about what should be funded and why. The funds are appropriated to NCI and this agency issues Requests for Proposals (RFPs) for research funding. Based on the RFPs, NCI then releases the funds for research activities. Though ACS supports the research priorities set by NCI, ACS determines it own research priorities and decides how the funds that are raised through donations will be spent (NCI and ACS, 2006).

Research has identified three main causes for breast cancer: genetics, lifestyle choices and environmental carcinogens. The literature has shown that only 30% of breast cancer cases can be directly linked to genetics and lifestyle choices, while the remaining 70% may be linked to the environment. Despite this fact, current research funding policies continue to focus the bulk of available funding on first two causes (Epstein & Steinmen, 1997:2-10; Epstein, 2003; Evans, 2006). There seems to be a disparity between the number of breast cancer cases that can be linked to a particular cause and the ratio of funds that are spent on research activities to reduce the impact of that cause. This disparity raises questions about how and why certain causes are funded and others are not.

Two Main Discourses

A review of the literature has identified two main discourses to answer these questions about the funding disparities: the conventional discourse and the alternative discourse. The conventional discourse explains existing research funding policies as set

by the NCI and ACS. The alternative discourse utilizes the "Cancer Establishment" and the "Cancer Industry" to explain the research funding policies.

Conventional Discourse: ACS & NCI

The Conventional Discourse consists of the NCI and ACS and their current views about research funding policies for breast cancer. The NCI was formed by the passing of the National Cancer Act in 1971 and this agency has been conducting research to fight cancer since that time. The mission of the NCI is (NCI, 2007):

> **"***The National Cancer Institute (NCI) is a component of the National Institutes of Health (NIH), one of eight agencies that compose the Public Health Service (PHS) in the Department of Health and Human Services (DHHS). The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training. The National Cancer Act of 1971 broadened the scope and responsibilities of the NCI and created the National Cancer Program. Over the years, legislative amendments have maintained the NCI authorities and responsibilities and added new information dissemination mandates as well as a requirement to assess the incorporation of state-of-the-art cancer treatments into clinical practice.*
>
> *The National Cancer Institute coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. Specifically, the Institute:*
>
> - *Supports and coordinates research projects conducted by universities, hospitals, research foundations, and businesses throughout this country and abroad through research grants and cooperative agreements.*
> - *Conducts research in its own laboratories and clinics.*
> - *Supports education and training in fundamental sciences and clinical disciplines for participation in basic and clinical research programs and treatment programs relating to cancer through career awards, training grants, and fellowships.*
> - *Supports research projects in cancer control.*
> - *Supports a national network of cancer centers.*
> - *Collaborates with voluntary organizations and other national and foreign institutions engaged in cancer research and training activities.*

- *Encourages and coordinates cancer research by industrial concerns where such concerns evidence a particular capability for programmatic research.*
- *Collects and disseminates information on cancer.*
- *Supports construction of laboratories, clinics, and related facilities necessary for cancer research through the award of construction grants."*

Funding for breast cancer research is a major priority for NCI. Figures P-5 shows NCI's current funding priorities for breast cancer research. The bar graph in this figure shows that NCI's funding for breast cancer research has increased since the year 2000. The pie chart shows how this funding is distributed and the overall funding priorities: early detection through screening, treatment, causes, biology, and survivorship programs receive the bulk of the funding. These research priorities connect with two of the three causes that have been discussed: genetics and lifestyle choices. The third cause linked to breast cancer, environmental carcinogens, is not shown on this pie chart; though the NCI does spend about 5 % of the annual research budget on the role of the environment as a cause for breast cancer.

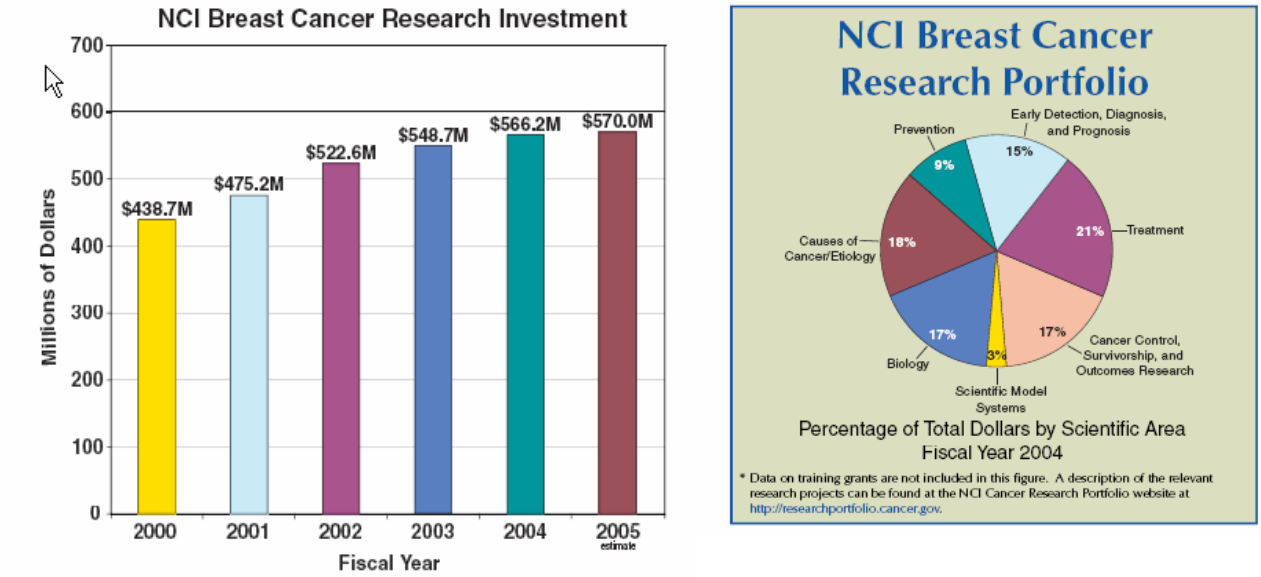


Figure P-5: Research Funding Investment: "A Snapshot of Breast Cancer".

The American Cancer Society (ACS) was founded in 1913 by physicians and business leaders in New York City. Since its formation, this organization has been working to raise awareness about cancer, conducting research for treatment and cure, and providing support for cancer survivors and victims. The mission of the ACS is (2007):

> "*The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service".*

The ACS raises a great deal of funds to help fight cancer. They use these funds to support many activities related to cancer including research. Breast cancer is one of the

cancers which receives research funding from the ACS. The funding priorities for these research activities are bulleted below (ACS, 2006):

> *"The money raised through Making Strides Against Breast Cancer helps the American Cancer Society fight breast cancer by …*
>
> - *Funding cutting-edge research leading to the discovery of lifesaving treatments like Tamoxifen and Herceptin. In fact, the Society has invested more in breast cancer research grants over time than any other voluntary public health organization – $322.7 million since 1972 and, it was the American Cancer Society that established mammography as the gold standard for the early detection of breast cancer.*
> - *Offering the nation's only 24-hour cancer hotline (1-800-ACS-2345), where people fighting cancer can turn anytime, day or night to talk to a Cancer Information Specialist (Information is available in many languages.)*
> - *Providing free programs and services that improve the quality of life for cancer patients and their families in more than 3,400 communities across the country*
> - *Providing free email mammogram reminders, and a program called Reach to Recovery® that matches newly diagnosed breast cancer patients with survivors who can guide them through their journey with the disease*
> - *Offering a state-of-the-art Web site (www.cancer.org) where patients can learn how to reduce their cancer risk, find hospitals, learn about treatment options and clinical trials, and more*
> - *Advocating for public policies that provide all women access to mammograms and breast cancer treatment, regardless of income*
> - *Since 1993, 3.5 million walkers across the country have raised more than $230 million through Making Strides events to help fight breast cancer. Thanks to people like you, the American Cancer Society provides help and hope to thousands of breast cancer patients."*

The ACS also focuses the bulk of the funds that are raised for breast cancer on research activities which focus on genetics and lifestyle choices. The role of the environment as a cause is not a research priority for the ACS, based on the information provided above.

The National Cancer Institute and American Cancer Society support funding for

research activities which target genetics and lifestyle choices. The NCI and ACS provide the following explanations for the increased incidence of breast cancer and their research funding policy focus:

- women are living longer and there are better screening methods to detect breast cancer earlier when possible;
- it is difficult to study the effects of the environment and conclusively pinpoint how environmental carcinogens cause breast cancer;
- medical treatment saves lives once the disease has been contracted;
- raising awareness about the impact the lifestyles choices can lead to adequate prevention activities (NCI & ACS, 2006).
- data about the role of environmental carcinogens is not readily available and there is limited understanding of how these carcinogens and endocrine disruptors work (NCI & ACS, Davis, 2002).

Alternative Discourse: Cancer Establishment & Cancer Industry

The alternative discourse consists of the Cancer Establishment and the Cancer Industry. Samuel Epstein, a professor and the Chair of Environmental Medicine at the University of Illinois, School of Public Health, who has published hundreds of journal articles as well as authoring and co-authoring 10 books; uses the term "Cancer Establishment" for the "the powerful lobby" which encompasses: NCI, ACS, and the twenty or more comprehensive cancer centers funded by NCI and ACS (Epstein, all three references). He explains that the "Establishment" is influencing research funding policies and hence deciding what to include and what to exclude in the national research agenda

and activities for cancer, specifically breast cancer (Epstein S.S, 2003; Epstein S.S, 1998,: Epstein S.S, 1997).

In his book *Breast Cancer Prevention Program*, Epstein goes into detail about how for the past two decades the Cancer Establishment has received and spent well over $20 billion dollars on the war against cancer, and the rates for cancer, specifically breast cancer are still on the rise. The Establishment continues to focus on research into genetics, screening, and treatment options, instead of the environmental carcinogens that can be specifically linked to the disease. Epstein explains that the Cancer Establishment sets the policy agenda for cancer funding research activities, including the research agenda for breast cancer.

Epstein and others who agree with the notion of the "Establishment" have published several books and reviewed well over 2,500 publications and documents which all seem to conclusively point to the fact that breast cancer can be prevented through the mitigation of environmental carcinogens and by limiting exposure to these carcinogens (Evans, 2006).

Epstein goes further to explain that the Cancer Establishment has a vested interest in keeping the research funding policies focused on screening, treatment, and basic genetics, rather than prevention by limiting exposures to environmental carcinogens. The Establishment consists of powerful appointed leaders who have conflicts of interest due to interlocking financial investments between those in power at NCI, ACS, and the pharmaceutical industry; also there has been a continual pattern of employment of pharmaceutical industry CEO's as the Directors of NCI; profit from drug development and marketing; ACS's connections to the mammography industry; and the media

campaigns which create smoke screens and legitimize the funding decisions. Epstein's view on cancer research, specifically breast cancer research can be summed up by the following quote: "Whether against cancer or terrorism, war is best fought by preemptive strategies based on prevention rather than based reactively on damage control. As importantly, the war against cancer must be waged by leadership accountable to the public interest and not to special agenda private interests." (Epstein et al, 1997, 669-707).

Based on his research, Epstein outlines the "dirty dozen", the risk factors that women can avoid to prevent breast cancer. The "dirty dozen" list includes: prescribed oral contraceptives; estrogen replacement therapy; premenopausal mammography; nonhormonal prescription drugs, such as anti-depressants; silicone breast implants; diets high in animal fat containing hormones; household chemicals; proximity to hazardous waste sites; occupational exposures to carcinogens; inactivity; dark hair dies; and prolonged alcohol and tobacco use (Epstein & Steinman, 1997:9). Though he provides a plan for how women can prevent breast cancer by becoming aware of and limiting exposure to the risk factors, and he alludes to the Cancer Establishment having a vested interest in treatment and screening research; however, Epstein's concept of the Cancer Establishment does not explain the mechanisms of how and why the research funding policies exclude the environment. The concept of the Cancer Establishment points to powerful leaders setting the agenda for research funding policies; it does not explain the role of power in agenda setting and socializing American society to accept the existing breast cancer research funding policies as adequate.

The Cancer Industry

The Cancer Industry is a concept which emerges from a book by Ralph Moss (Moss, 2002). Moss is a well known medical writer who has been studying cancer policies since the 1970's. He defines the "Cancer Industry" as the underlying economic system or mechanism of profit making that excludes research into environmental carcinogens, prevention, and alternative medicine, because they are less profitable. He declines the notion of the agencies utilizing power to maintain their agenda, rather he blames the economic and social systems in place that are driven by profit (Moss, 2002). He does agree that the "ruling class" in cancer research is comprised of pharmaceutical companies which have emphasized the dominant discourse of medical treatment instead of prevention; however, this ruling class is more influenced by the economic system of profit which suppresses the less profitable methods (Moss, 2002).

The "Industry" consists of the government, medical centers, drug companies, equipment manufacturers, and the media (Moss, 2002). Together they act to suppress the less profitable treatments and call them unorthodox methods that do not have proven results of success (Moss, 2002). The Industry wants to continue to engage in drug therapies and screening methods which may actually be sources of the carcinogens that contribute to breast cancer. The Industry defines the medical treatment practices and research funding and policies. Most research funding policies are fixated on secondary and tertiary prevention- through screening and medical treatment, when research should also focus on the elimination of environmental carcinogens leading to primary prevention (Epstein, 2003).

This system or predominant Industry is driven by profit from screening and treatment techniques, such as mammography and chemotherapy. In fact, he calls the NCI the political pharmacy where new drug therapies are formulated to fight breast cancer and the research on prevention, the environment, and alternative medicine are discouraged (Moss, 2002). Though there have been programs developed to investigate alternative medicine, these programs receive little to no funding for research activities. The mechanism of discouragement takes form through restricting research on certain topics by decreasing or eliminating funding (Gennaro, 2005:356-359). Though science can contribute to prevention, environmental, and alternative medicine research; unregulated scientific research can have the potential to topple this Industry (Moss, 2002). Therefore, the Cancer Industry, for sake of self preservation, has mechanisms in place to control scientific research that may impact the profit margin (Moss, 2002).

The Cancer Establishment and the Cancer Industry combine to form the alternative discourse for explaining why research funding policies for breast cancer may be decided. The next section will utilize Sociology and Policy Theories to expand this discourse and provide insight into why power and market systems may influence breast cancer policies and how these influences impact the policy process.

Theoretical Framework

Social Theory

Sociology can provide background for the influence that power and economics can have through scientization of politics on the policy process. For the purposes of this study, power will be defined by two social theorists and an attempt will be made to

explain the role of power in breast cancer research funding policies. The first is Steven Lukes. Lukes is known for defining the "Three Faces of Power" or the three levels of power a government has to create social order in a given society and to legitimize views and rules of those in power. These three levels are:

1) The public process of policy making where the prevailing public and opposing parties are involved in decision making or defining the winner;
2) Agenda setting or framing which is more subtle, yet very powerful because it is not as obvious;
3) The power to socialize people so that they reflect the view of the person in power (Lukes, 1974).

These three levels of power can drive the policy process. An example of the first would be the questions that are placed on a ballot for the general public to vote. The public votes yes or no and decides the outcome. This level of power tends to be more obvious and not as heavily utilized to determine policy. The second level of power, agenda setting, is utilized heavily in policy process. An example of this level would be process of deciding which questions will appear on the ballot for voting. The third level of power involves actually shaping the view of individuals so that they reflect the ideology of those in power. Using the example of the questions on the ballot, this level of power would actually shape the view of the voters so that they vote in favor of the ideology in power (Lukes, 1974).

Of these three levels of power, the latter two: the power to set agendas and socialize people are used to influence the research funding policies for breast cancer. Though the policy makers and the general public may believe that science is driving the

research activities towards funding for two of the three causes, genetics and lifestyle choices; the truth is that leaders of the NCI and ACS may be determining the research agendas for breast cancer and other diseases.

NCI and ACS set the agenda for breast cancer research activities by: influencing appropriations for research and prescribing research activities that will be funded. Influencing appropriations occurs during Congressional hearings and the prescribing research of activities occurs once the agency receives the funds.

The type of agenda setting that can occur during the hearing process can be explained by the "scientization of politics". The Scientization of Politics is a theory developed by Jurgen Habermas and later utilized by Urlik Beck in the book *Risk Society*. This theory explains how science has become encapsulated by governmental bureaucracies and involves a research process which is defined by technical applications; rather than by research for the sake of solving problems. Scientific knowledge and research results are no longer communicated to the public and instead the information is controlled by experts. Decisions that should be made based on politics and morals, are transferred into scientific arenas which complicate the fact and exclude the public. The public has no real dialog about science, creating a non-democratic state which seems to exclude the public completely. Science has become a contracted set of research activities which agencies and politicians can use science and scientific experts to provide data for the cause they want to be validated or legitimized (Habermas, 1970: 62-80; Beck, 1992). Science can no longer explain away the risks to the public, since there are scientific experts employed by the government and industry with conflicting interpretations about the research results leading to inconclusive decisions by the government and no answers

about the risk associated with this technocratic society for the public. Science is no longer the pure search for solutions, rather it has become a competition between experts on both sides of the issue and in the end the results are influenced by the industries funding the scientific research, instead of the actual research data (Fischer, 2000: 87-108)

Breast cancer research involves conflicting views from different scientific experts and theses conflicts are emphasized during the policy process for research funding. Politicians have influence over the type of funding and who should receive that funding for breast cancer research activities and the scientist that perform these activities. The scientists reinforce the politicians' decisions with scientific data leading to the scientization of politics (Habermas, 1970: 62-80). Since the environmental causes of breast cancer could lead to the toppling of the industries which produce the pollution; scientific experts are utilized to provide inconclusive data which cannot establish the risk from the sources of pollution and the true risk is not communicated to the public.

This scientization of politics reinforces how the second level of power can influence breast cancer research funding for certain causes instead of others during the policy process in the United States. Those in power are not only defining the dominant discourse for research funding; they are also developing methods of legitimizing their funding decisions by utilizing empirical testing and data to support their decisions (Camhis, 1979). Scientific experts provide politicians with the research agenda and data to support current research funding focused on two of the three causes. These agendas are presented at Congressional hearings and supported by the testimony presented by those who appear at the hearings to drive the research funding policies. Policy makers are provided with status reports on current research activities, along with the results and

statistics which promote or demote certain research activities (NCI & ACS reports). Hence, the agenda setting becomes a powerful tool to maintain the existing research funding activities.

The Sociology of Science is a sociological concept that can add to this discussion of the scientization of politics. This concept explains that science is more than the search for the truth or answers to unexplainable phenomenon as it was in the time of Newton or Einstein; it has become a cultural tradition and as such has been institutionalized (Ben-David and Sullivan, 1975:203-222). Just as science can impact the societal activities such as the creation or reduction of pollution through different technology; societal inputs can impact the nature of scientific activities. For example, one of the main activities of science is research and these research activities are now directly impacted by grant funding. No longer does a scientist conduct research without some form of grant funding from an institution. The institution provides research funding if the proposed research activities match the issues the institution wants to have researched. The science of sociology examines how science is controlled and maintained by the virtue of the research activities and the fact that science no longer determines the unexplained phenomenon to be researched; the government and industry set the research agendas (Ben-David and Sullivan, 1975:203-222).

Research activities can lead to scientific discoveries and impact changes in sciences and future research activities. So the organizations which control the research funding not only impact current research activities; but also future research and science as a whole. Science is no longer the quest for individual knowledge for the betterment of society; it now consists of research activities that are controlled heavily by funding and

societal norms which dictate these activities (Gentili, 2000: 12-18). Governmental institutions, academic universities, and industry define the norms or acceptable research activities; research activities that may be considered as deviant or challenge the accepted norms are often excluded from receiving research funding (Agnew, 1998: 6-7). Science has become an institution which conducts research activities that will provide economic benefits to the organization that is granting the funding for the research activities. The science of sociology explains how science has moved away from the individual quest for knowledge to an institution which is controlled by the privatization of research funding and those agencies which set the research agendas.

This leads to the prescribing of funding for research activities which occurs during the agenda setting of Request for Proposals (RFPs) for grant funding. RFPs are issued and researchers and agencies, such as universities, compete for funding. The agenda setting is accomplished in the RFPs by prescribing the types of research activities that will be funded (Epstein, 2003; Moss, 2002). Agencies which submit proposals that do not align with the prescribed agenda for research activities are not funded (Epstein, 2003).

The third level of power is also utilized for setting the policies for funding breast cancer research. This level of power involves shaping the view of individuals so that they reflect the ideology of those in power. In the case of research funding policies for breast cancer, the pink ribbon has been engraved into American society convincing the people that an annual fundraising campaign is enough and questioning research funding policies or where the funds raised through donations are going is unnecessary (Kolker, 2004:820-844). This ribbon can be identified as a breast cancer symbol by even a small

child. This disease has received a great deal of press and though the press has helped women to not have to suffer in shame; it has also created a false sense of hope, socializing women to believe that the annual "Race for the Cure" and wearing a pink ribbon is enough (Epstein, 2003, Kolker, 2004:820-844).

The other aspect of using power is also emphasized by the alternative discourse and how the NCI and ACS exercise their power in the area of breast cancer research with intention. The notion of using power with intention coincides with Mike Foucault's definition of power. Foucault explains that knowledge and power combine to define the dominant discourse which sets up what is normal and abnormal (Foulcault, 1990, 1995). This dominant discourse of normal and abnormal is then adopted by those in power and their view is reflected in the research funding policies.

Foucault emphasizes the role of how shared ideas, or paradigms, change or shift based on old theories being challenged and replaced with new theories to form dominant discourses. He explains that dominant discourses are formed because of power and by those in power. Power is what drives the shifts in paradigms. Those in power, use the power to impose their own paradigms on the community (Skinner, 1985:Chapters 6 & 7). Power is used to define the dominant discourse for research funding policies for breast cancer.

Power is also used to influence the policy process and increase profit for the Cancer Industry. How profit and the market system develop the ideologies which dominate the breast cancer funding policies, can be explained by Karl Marx's theory about the capitalistic mode of production and Allen Schainber's treadmill of production. In the capitalistic mode of production, everything, including all of the inputs and outputs,

become commodities and are commodified (Sweezy, 2004: 1-10). At the top of this market system tend to be a small group of individuals pursuing interests, keeping each other in check by competition. These inviduals are the "ruling class", those who control the production or policy agenda and that set the ideologies in motion for the market system to run. The purpose of this market system is to maximize profit, not provide services focused around people and their health or well being (Sweezy, 2004:1-10). This theory of the mode of production emphasizes how the ideals of the Establishment and Industry become institutionalized in the decision making process to determine research funding outcomes for breast cancer (Sweezy, 2004:1-10). Profit from medical treatments and screening methods drive the policies for funding and create a Cancer Industry.

The notion of the Cancer Industry can also be captured by Allan Schainber's "treadmill of production" (Foster, 2005:7-18). The treadmill of production is a framework of analysis for environmental sociology and can be applied to the Cancer Industry. In his article "The Treadmill of Accumulation", Foster explains the six elements behind the logic of this concept: increasing accumulation of wealth by a small group of people in society; workers moving away from self-employment to wage jobs; competitive struggles between businesses leading to new technologies and expansion of production; an insatiable hunger for more; government increasingly promoting a national economy; and the dominant means of communication and education serve to reinforce the priorities and values of the treadmill of production (Foster, 2005).

The treadmill produces goods and is driven by consumption, regardless of the consequences. Driven by the capitalistic constant need for more, production and consumption are increased, raw and natural resources are depleted at exponential levels and pollution is created (Sweezy 2004:1-10; Foster, 2005). All resources are viewed as commodities, including medical treatments. As production and consumption are increased, so are profits which drive companies to increase competition and advertising which influences the consumer choices and reinforces the cycles of production and consumption (Foster, 2005). The Cancer Industry is an example of this treadmill of production. The Industry is in this cycle driven by profit to produce treatment and screening options which produce more profit, thus making cancer a profitable industry (Moss, 2002).

Another facet of what may be influencing research funding policies has to do with the role of patriarchy in the selection of those who decide on the research funding policies. There may be a lack of a female presence on the voting boards of industry or government agencies which determine the research funding policies. Due to the fact that breast cancer is a woman's issue, patriarchy may play a role in determining the decision makers for research funding policies since women may not be present during the conversation that determines the policies for research funding. Marxist Feminist theory can explain how women may be excluded.

As Marxism speaks to the exploitation of the worker class by capitalism; feminism speaks to the exploitation of the female gender by patriarchy (MacKinnon, 1982; Shelton and Agger, 1993; Hartsock, 1998). Both of these theories point to notions

of oppression and just as the worker class may be excluded from participation in the policy process by capitalism; females may be excluded from participation in the breast cancer research funding policy process by patriarchy. The theories presented earlier in this chapter have provided some of the potential reasons why the environmental causes of breast cancer have been excluded from research funding such as power and economics, Marxist Feminism may also provide evidence for the role of patriarchy in the policy process. Therefore it is important to acknowledge the gender of those involved in the conversation that occurs about the breast cancer research activities and the research funding policies.

Policy Theories

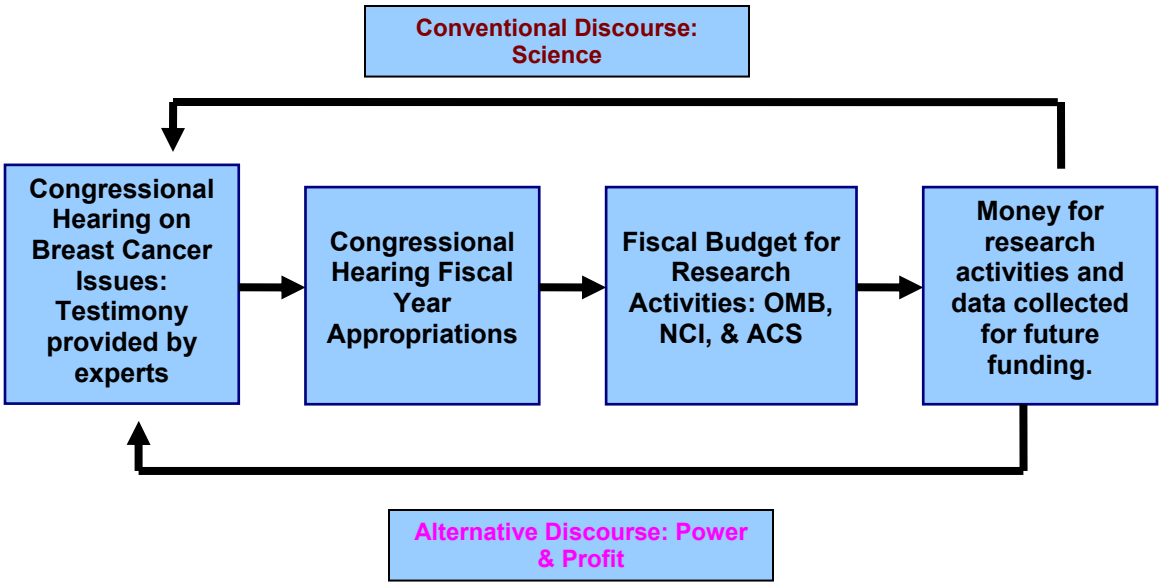
The social theories of power, scientization of politics, market system, and treadmill of production provide the background for why the research funding policies are made. These theories can be associated with policy theories, to help better explain how these issues impact the policies that are made in the United States. William Domhoff, explains several policy theories in his paper "Who Rules America?: Alternative Theoretical Views". These theories are: Pluralism, State Autonomy, Elite Theory, and Marxism. These theories are defined below (Domhoff, 2005):

- Pluralism: which is the theory that is based on the idea that different groups have power depending on the issue and that there is a free-market system;

- State Autonomy: explains that the government is an independent force that uses military control to maintain power;
- Elite Theory: states that the leaders of large organizations or bureaucratic institutions dominate societies;
- Marxism: emphasizes that property owners rule the policy process.

Though there are other policy theories that can be used to explain the policy process, such as: Group Theory, Rationalism, and Systems Theory; for the purposes of this research only the Marxism and Elite Theory will be further expanded, since they best relate to the alternative discourse. Since the Social Theory section of this chapter has discussed Marxism by explaining the market system and capitalistic mode of production; only an explanation of Elite Theory will be provided.

As defined above, Elite Theory attempts to explain how power relationships and economic stature impact the policy process. This theory emphasizes how the small minority of individuals who hold economic power, control policy planning networks, which can lead to the policy agendas that are set and the policies that are implemented (Domhoff, 2005; Lavis, J, 2002). In the case of policies for breast cancer research activities, NCI , ACS, and other NGOs can be considered as the elites. The model on the next page shows the policy process and how the two discourses may impact this process.



This model displays how the policy process for research funding occurs. Congress convenes hearings on policy issues associated with breast cancer, including policies for research funding. Different agencies and actors are invited to testify at the hearings and based on the testimony, funding decisions are made and funds are allocated and awarded for research activities. The conventional discourse emphasizes that the policy process is driven by science and the alternative discourse emphasizes that this policy process is driven by power and profit.

Though Marxism and Elite Theory support the alternative discourse of Cancer Establishment and Cancer Industry; they do not capture the other parameters that are present in the policy process. These two theories also do not explain fully how and why breast cancer policies are made and the role of the conventional and alternative discourses play in the determination of the actual research funding policies for breast

cancer. The policy process is dynamic and it involves networks and feedback loops which facilitate change. The Advocacy Coalition Framework combines the various components of the policy theories to explain how the policy process works (Blackburn, pp.54-58).

The Advocacy Coalition Framework (ACF) can be used to determine policy outcomes in situations where there is conflict about what should be funded. The ACF provides a mechanism for reviewing how competing advocacy coalitions, changes in external subsystems, and a stable system of parameters impact policies (Jenkins-Smith, 1993). The competing advocacy coalitions are the actors from public and private institutions at varying levels of government that share belief systems and work to manipulate the policies to match these beliefs. The external subsystems are the economic and other systems that impact these coalitions in their quest to manipulate the policy process. The stable system of parameters are the rules or the social structures that set the constraints for the policy process (Jenkins-Smith, 1993).

The ACF explains that the policy process involves competition between the advocacy coalitions to establish and maintain core elements of public policy; as these dominant coalitions change over time so do the external subsystems and ultimately the policies (Jenkins-Smith, 1993). The ACF has been utilized to study the policy process and better understand the coalitions or stakeholders and their influence on the policies that impact the environment and the role of the environment. Weible, in his article entitled "An Advocacy Coalition Framework Approach to Stakeholder Analysis: Understanding the Political Context of California Marine Protected Area Policy", utilizes the ACF to analyze the role of stakeholders in the political battle over protected areas for

marine life in California. He illustrates how the varying stakeholders work in the context of the ACF to promote their individual agendas (Weible, 2006).

The ACF has also been used to describe coalitions and their impacts on automotive pollution control process. The ACF was used in this automotive pollution study to determine how groups of actors coordinate their actions to compliment and achieve the overall policy objectives to coincide with their beliefs or ideas (Zanfonte, 2004). In this study the ACF is used to recognize the struggle over ideas and beliefs that occur during the policy process. The ACF specifies that shared beliefs amongst actors leads to network relationships that align to form coalitions, unified discursive frames, and influence the policy process (Weible, 2005). The ACF has been used to understand the policy process and to conduct policy analysis on other environmental issues and specifically with policy elites and how they engage to form coalitions to promote their shared belief systems and influence the policy process (Leach, 2005). The ACF has been used in the analysis of air pollution and the formation of air quality policies where there are strong advocacy coalitions, and market systems in place to drive the policies in different directions. For these reasons, the ACF provides the framework needed to analyze the research funding policy process for breast cancer and determine how and why certain causes receive funding, while others do not (Jenkins-Smith, 1993).

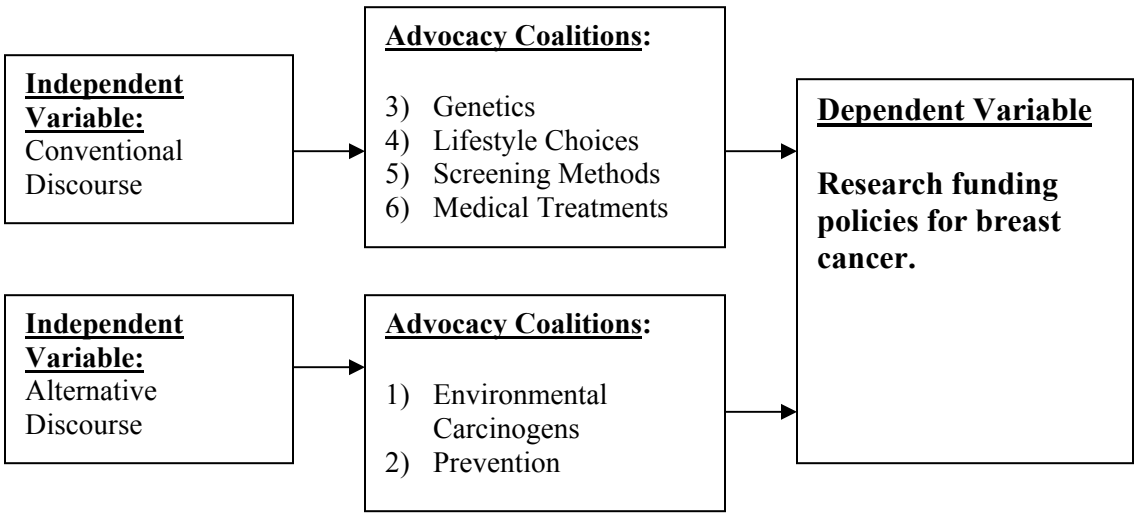
In the case of research funding policies for breast cancer, there are actors and agencies who share certain core beliefs about research funding based on the conventional and alternative discourses. The two discourses stem from the potential funding priorities based on the three causes which have been linked to breast cancer: genetics, life style choices, and environmental carcinogens. Different actors and agencies join around

these two discourses and form the six advocacy coalitions who share similar core beliefs or discursive frames about what the research funding policies for breast cancer should be. These six coalitions are:

- Coalition A: Research into Genetics
- Coalition B: Research into Lifestyle Choices
- Coalition C: Research into Screening Methods
- Coalition D: Research into Medical Treatments
- Coalition E: Research into the Environment
- Coalition F: Research into Prevention

Coalitions A through D represent the "actors" or agencies that share core beliefs or the discursive frame with the conventional discourse. Coalitions E and F represent the alternative discourse and the agencies or actors who believe and represent the discursive frame that research funding policies are influenced by power and profit.

The model on the next page visually represents the mechanism for research funding policies for breast cancer. The two boxes on the left represent the two main discourses or discursive frames which may influence research funding policies for breast cancer. These two main discursive frames represent the core beliefs of the various agencies and actors that join together to form the six advocacy coalitions- the middle two boxes. These advocacy coalitions then testify in favor of or against the policies that are discussed during the congressional hearings, which leads to the eventual formation of the research funding policies for breast cancer (the box on the right).



Though the actors and agencies who testify or take part in the breast cancer hearings will be determined during the actual research phase of this study, there are several agencies and actors who may be expected to testify during breast cancer hearings:

Agencies: National Cancer Institute, American Cancer Society, Susan G. Komen Foundation, and the National Breast Cancer Coalition.

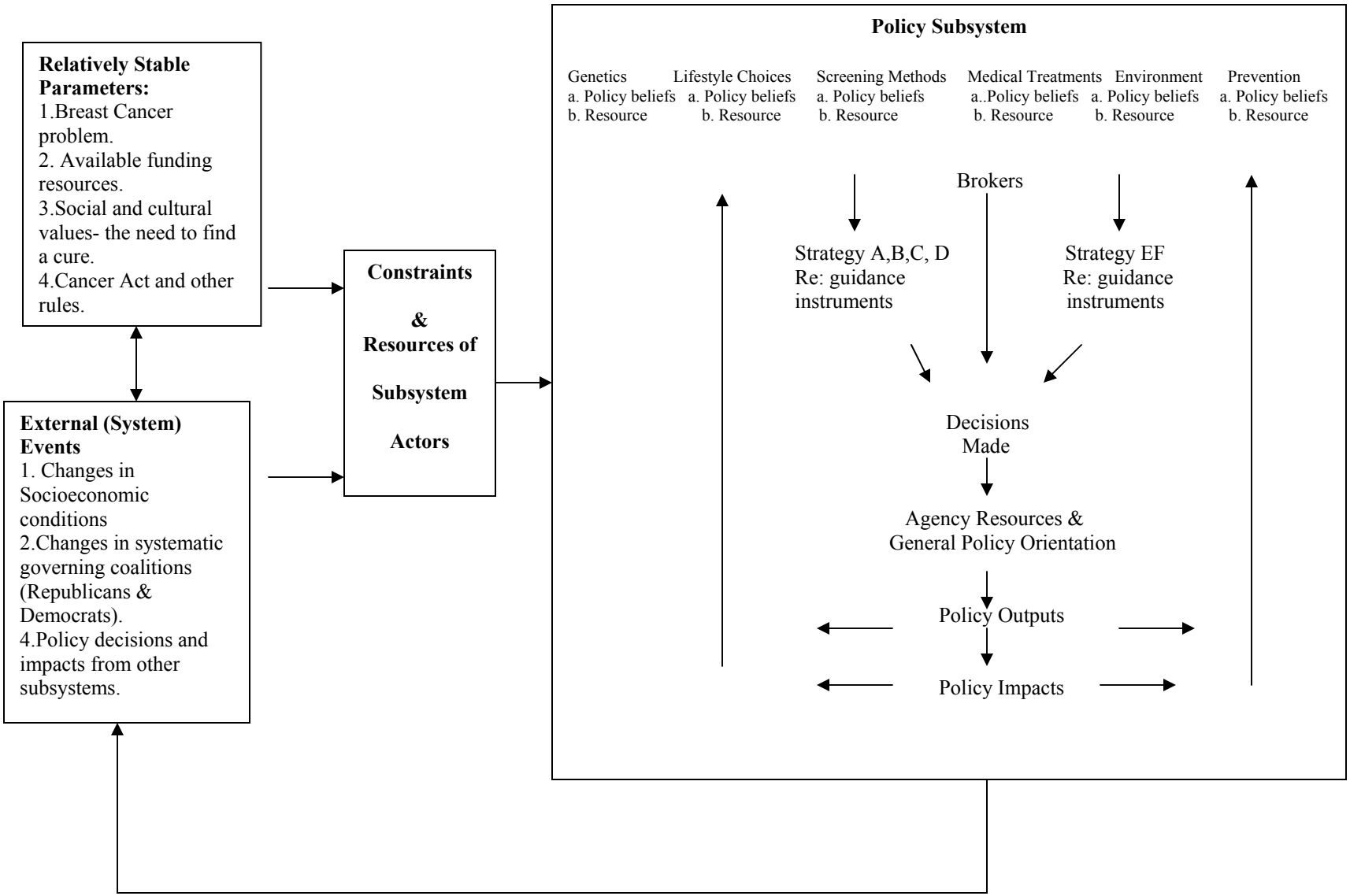
Actors: The actors who testify will be the directors, presidents or CEOs of these agencies.

The remaining components of the ACF for breast cancer research funding policies are:

- External subsystems: economic conditions and incident and mortality rates for the disease;
- Relative stable parameters: such as the Cancer Act and the availability of resources.

All six of the coalitions compete to drive the policy process and form research funding policies for breast cancer. Figure P-6 on the next page depicts the ACF for breast cancer research funding policies.

Figure P-6: The Advocacy Coalition Framework: for Breast Cancer Research Funding Policies



Rationale for Using Congressional Hearings

Though the ACF provides the framework for studying the policy process which determines researching funding activities for breast cancer; it does not define how to study the policy process. In "Social Movements, Field Frames and Industry Emergence: a culture-political perspective on US Recycling", Lousenbury and others examine how social movements work to impact institutional change and the creation of new industries. Recycling, which started as an environmental movement became mainstream and institutionalized (Lounsbury, 2003:71-104). This paper explains how changes in policy or the views of institutions depend on infrastructure of existing networks, associations, organizations, and government. Details are provided about how field frames are introduced, maintained, or changed in policy arenas such as Congressional hearings (Lounsbury, 2003:71-104).

Congressional hearings provides a written record of the discussions about policy issues, the actors and agencies involved in these discussions and how all of these combined form or change policies. These hearings provide a narrative text of the policy process discussion and the key actors that took part in this discussion to impact the creation or change of a policy (Lounsbury, 2003:71-104). In order to better understand how the funding is determined during the congressional hearings, it is important to understand how Congress determines the federal budget and the steps involved in the budget process. The budget process includes four phases (Dodd and Oppenheimer, 1993:48-80):

1) Preparation and submission of the budget by the President;
2) Congressional action on the President's proposed budget;

3) Execution of the budget related laws;
4) Audit if agency spending.

In order to address all four of these phases, Congress holds Authorization and Appropriation hearings in addition to normal policy related hearings. The Authorization hearings determine the legislative issues or policies that require funding (Dodd and Oppenheimer, 1993:48-80). The Appropriations hearings actually determine the amount funding that will be provide to each program. Certain programs are automatically funded due to the fact that they are required by law, such as the NCI (Dodd and Oppenheimer, 1993:48-80). The congressional hearings, whether they are authorization or appropriations hearings, provide a written record of the agencies and actors who testified and the nature of their testimony. The hearings for breast cancer will help determine this information so that the ACF can be utilized.

Congressional hearings will provide the medium for using the ACF for policy analysis, in order to understand how and why breast cancer research funding policies set priorities for certain causes instead of others. These hearings are not considered democratic, instead groups or agencies are invited to speak or they request to provide testimony. Based on the topic and requests, decisions are made about who will testify and for how long. The hearings provide Congress with information about certain policy topics and coalitions the opportunity to lobby for a particular cause (Miller, 2004; Svihula, 2007).

Major Findings

This literature review has provided information about the epidemic of breast cancer in the United States. The etiology, as well as the research details about the three causes for breast cancer has been provided. The conflict between the research funding policies compared to the statistics on the actual causes of breast cancer has also been outlined. This literature review has explained the disparities that exist between the actual causes of breast cancer and the ratio of funding these causes receive.

Two discourses were identified that may explain the reasons for these disparities: the conventional and the alternative. These discourses were expanded by using social and policy theories about the role of power, market systems, and scientization of politics to explain how and why breast cancer research funding policies may be established and maintained.

Major Gaps

The major gap that has been identified from this literature review is that there seem to be funding disparities in breast cancer research activities. In order to determine how and why these disparities exist, an analysis of the existing breast cancer funding policies needs to be conducted. The ACF has been used to analyze policy processes for various environmental issues; however, it has not been used for studying the policy process for breast cancer research funding policies. This dissertation purposes to apply the ACF and utilize the Congressional hearings for breast cancer research funding policies to determine if there is a systemic exclusion of research funding for certain

causes of breast cancer and if in fact there are power and market system forces which are driving the research funding decisions.

Innovation and Significance

This research provides two levels of significance: theoretical and practical. The theoretical innovation and significance of this work lies with utilizing the ACF and Congressional hearings to determine the role of environmental carcinogens on breast cancer causation. Though the ACF has been utilized to analyze the policy process for other environmental policies, it has yet to be used to analyze the role of environmental causation of a disease. This work will contribute to the current body of literature for the use of the ACF and provide an example of how Congressional hearings may be used to show power dynamics during the policy process.

The practical significance of this work is that it will attempt to address the funding disparities for breast cancer and hope to shed light on how and why policies are determined and maintained. This research will be able to make recommendations about the research policies and possibly impact the existing research funding policies to shift and be more inclusive of the role of environmental carcinogens on breast cancer causation.

CHAPTER 3: METHODS

Overview

Chapter two provided the etiology of breast cancer; a glimpse into the current research funding policies for this disease; an explanation of the two main discourses and the associated six advocacy coalitions that explain how and why these research policies are determined; the theoretical framework; and a summary of the major findings and gaps. The purpose of this chapter is to describe the methodology that was used. There are four sections in this Chapter: research needs; research design; sampling rationale, data collection; and data processing and analysis.

Research Needs

Chapter two revealed that there is a disparity between the existing funding priorities and the causes of breast cancer. There is a need for research into funding policies for breast cancer to determine the reasons for the disparity. There are many studies which identify the environmental carcinogens that are linked to breast cancer occurrence, but none that determine how and why the research funding policies do not focus on funding research activities for the environmental causes of breast cancer.

In order to determine how and why research funding policies for breast cancer are formulated and if in fact these policies systematically exclude funding for the role of environmental carcinogens, this study applied theoretical arguments from sociology and utilize the Advocacy Coalition Framework (ACF). The ACF provided the adequate tool needed to conduct a thorough policy analysis on current breast cancer policies.

Research Objectives

The research objectives for this study were to determine:

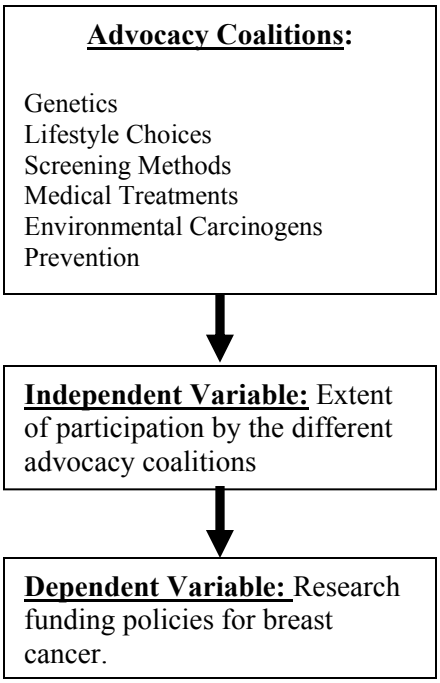
- If there are variations in the levels of advocacy for the different causes.
- If these variations impact research funding levels.
- If the amount differs by the advocacy coalition.
- If there is a funding mismatch.

Design

This work utilized a qualitative approach, though quantitative data will be collected. The research consisted of a cross-sectional design. A cross-sectional design was used because each of the Congressional hearings represent one time period. The overall approach will be a quantitative Content Analysis, which is the process of identifying, categorizing, and coding patterns of data in large amounts of textual information (Krippendorff, 2004; Patton, 371-389). This study proposed to analyze Congressional hearings about research funding policies for breast cancer to determine how and why funding priorities are determined. Content analysis provided a means of conducting both qualitative and quantitative analysis. The qualitative analysis was used to identify the predominant themes and the actors and agencies, hence the nature of the six coalitions. The quantitative analysis was used to provide the data on the amount of time each coalition was given or not given to testify (the length of testimony).

The literature identified two discourses which were linked to six advocacy coalitions that impact research funding decisions for breast cancer. These two discourses are: conventional and alternative; and the six advocacy coalitions are: genetics, lifestyle choices, screening methods, medical treatments, environmental carcinogens, and

prevention. It was determined that there could be multiple reasons for this research funding dynamic including: the culture or orientation of the agencies (NCI &ACS) charged with determining the research agendas; the training and knowledge of the experts setting the research agendas and actually conducting the research; and the involvement of advocacy and lobbying groups and the role they play in the agenda setting for research funding. By using the ACF and conducting content analysis on Congressional hearings, it is hoped that reasons for how and why the research funding policies for breast cancer are determined. Depicted below is a model to be tested:



The first hypothesis for this study was that research funding policies for breast cancer are driven by a policy process that is dominated by a combination of discursive coalitions which marginalize advocacy for research on the environmental causes of breast cancer.

The null hypothesis is: Ho- All discursive coalitions have equal participation in the hearing process.

The alternative hypothesis: Ha- The discursive coalition advocating research into the environmental causes of breast cancer is marginalized in the hearing process.

The second hypothesis for this study was that the higher level of advocacy for non-environmental causes of breast cancer results in higher funding level for non-environmental causes of breast cancer over environmental causes.

The null hypothesis is: Ho- Research Funding Priorities are not related to the different levels of discursive coalition participation in the hearing process.

The alternative hypothesis: Ha- Research Funding Priorities are related to the different levels of discursive coalition participation in the hearing process.

The third hypothesis for this study was that the economic interests of the presenter impacts the nature if the testimony for or against research funding on the environmental causes of breast cancer.

The null hypothesis is: Ho- The economic interests of the presenter does not impact the nature of the testimony.

The alternative hypothesis: Ha- The economic interests of the presenter do impact the nature of the testimony.

Sampling Rationale, Data Collection

Sampling Rationale:

Breast cancer has been a topic of Congressional hearings for several years. The breast cancer movement came into governmental existence in 1990 with the passage of the Breast and Cervical Cancer Mortality Prevention Act. Since then there have been approximately ten additional Acts about breast cancer and many associated Congressional hearings. A LexisNexis search revealed that there have been 128 Congressional hearings that have included breast cancer as a topic. Not all of these hearings, however, have dealt with issues relating to funding for research activities. Hence, the search for appropriate Congressional hearings for this study has to be narrowed to only included hearings that dealt specifically with appropriations for research funding policies for breast cancer.

Therefore the sampling criterion for inclusion in this study was: Congressional hearings that dealt with appropriations for research funding activities only. A modified LexisNexis search based on these criteria has identified 8 such Congressional Hearings; hence the sample size for this study will consist of these Congressional Hearings.

Once these hearings were selected, they were coded using Atlas.ti. In order to measure the research budget allocations, the budget data for the fiscal year following each of the hearings was collected from the United States Office of Management and Budget, NCI, and ACS to determine the allocations for particular research activities.

Variables

The independent variable for this study is: the extent of participation by the six advocacy coalitions defined below and the dependent variable is the research funding policies for breast cancer research:

Genetics: Defined as the study of heredity; for the purposes of this study, refers to the evidence that there are "breast cancer genes" which seem to be responsible for causing breast cancer: the BRCA1 and the BRCA2 genes (Steingraber, 2000 & Epstein 2003).

Lifestyle Choices: defined as smoking, alcohol consumption, diet, exercise, reproductive behavior, and driven by cultural beliefs, and social status (Steingraber, 2000 & Epstein 2003).

Screening Methods: Defined as tests and exams used to find breast cancer in people who do not have any symptoms; the three methods are breast self-exam, clinical breast exam, and mammograms (ACS, 2007).

Medical Treatments: Defined as medical intervention for a disease; for breast cancer, the treatment options can involve removal of the tumor, removal of the breast, chemotherapy, radiotherapy, and other medications (ACS, 2007).

Environmental Carcinogens: the environment, environmental pollutants and carcinogens that are considered as triggers for breast cancer causation (Epstein, 2003, 2005). Chemical pollutants produced by industrialization and are not the only environmental carcinogens, radiation and everyday items, such as cosmetics, pesticides, and household cleaning materials may also cause breast cancer (Brody, 2005).

Prevention: though usually associated with early detection and education about lifestyle choices; for the purpose of this study, prevention will be defined in relation to minimizing exposure to environmental carcinogens (Steingraber, 2000 & Epstein 2003).

Table P-1: Definition, Measurement and Source of Variables

CONCEPT	VARIABLE	MEASURES	SOURCE
Extent of Participation of the different advocacy coalitions in congressional hearings	1) Nature of the Discourse/Coalition: Genetics, Lifestyle Choices, Screening Methods, Medical Treatment, Environment, and Prevention	1) Discourse/Coalition of Speaker: Genetics, Lifestyle Choices, Screening Methods, Medical Treatment, Environmental Carcinogens, and Prevention	1) Coded from Congressional Hearing
Extent of Participation of the different advocacy coalitions in	2) Length of Testimony	2) Number of lines of testimony in the Congressional Record	2) Coded from Congressional Hearing

congressional hearings			
The relationship between the economic interest (s) and the nature of the testimony	3) Nature of the organization or advocacy of the presenter	3) The mission of the organization and funding interests	3) Coded from Congressional Hearing and the data from the organization's website
Research Allocations for Breast Cancer	4) Breast Cancer Research budgets for NCI and ASC.	4) Budget data following the fiscal year after the hearing	4) Office of Management and Budget, NCI and ACS Annual Reports.

Data Collection

The specific Congressional hearings were downloaded from the US Government Printing Office in the appropriate format that is needed for the data analysis program. Once these hearings were identified, the following steps were utilized to conduct the research:

1) Coded each Hearing- Atlas.ti and the coding sheet and instruction on the next page were used.

2) The predominant themes of each coalition were identified;

3) All of the information about each of the presenters and organizations which testified was identified and entered into an Excel spreadsheet;

4) Descriptive and statistical analysis was conducted.

Coding Instructions: For Congressional Hearings

A separate coding sheet will be completed for each hearing. Listed below are the codes and explanations for each characteristic:

1) Hearing Characteristics:

a. Title of the Hearing: as listed on the cover page
b. Date of the Hearing: as listed on the cover page
c. Name of the Committee that held the Hearing: as listed on the cover page
d. Name of Chair Person presiding over the Hearing: as listed at the beginning of the Hearing
e. State the chairperson represents: the initials of the state
f. Party affiliation of the chairperson: 0- Democrat, 1- Republican, 2-Other

2) Presenter Characteristics

a. Name of presenter: as it appears at the beginning of the presentation
b. Title or Position
c. Education and Years of Experience
d. Gender of Presenter
e. Name of Organization they represent: as it appears at the beginning
f. Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy,
g. Type of NGO
h. Nature of Advocacy
i. Type of Business Interests of NGO
j. Type of Corporation/Industry
k. How long the presenter spoke: Count number of lines

l. Topic and content of presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment ,6-Prevention

Coding Sheet for Breast Cancer Congressional Hearings

Hearing Characteristics:	
Title of Hearing	
Date of Hearing	
Name of Committee	
Name of Chairperson	
State of Chairperson	
Party Affiliation: 0- Democrat 1- Republican 2- Other	
Presenter Characteristics	
Name of Presenter	
Title or Position	
Education and Years of Experience	
Gender of Presenter	
Name of Organization	
Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	
Type of NGO	
Nature of Advocacy	
Type of Business Interests of NGO	
Type of Corporation/Industry	
Length of Presentation	
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment 6-Prevention	
Presenter Characteristics	
Name of Presenter	
Title or Position	
Education and Years of Experience	
Name of Organization	

Gender of Presenter	
Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	
Type of NGO	
Nature of Advocacy	
Type of Business Interests of NGO	
Type of Corporation/Industry	
Length of Presentation	
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment 6-Prevention	
Presenter Characteristics	
Name of Presenter	
Title or Position	
Education and Years of Experience	
Gender of Presenter	
Name of Organization	
Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	
Type of NGO	
Nature of Advocacy	
Type of Business Interests of NGO	
Type of Corporation/Industry	
Length of Presentation	
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment 6-Prevention	

* The electronic coding sheet will continue until every presenter for each hearing is captured.

Validity and Reliability

There are issues that arise regarding validity and reliability with any social science research method. Validity for content analysis involves insuring if in fact the inferences drawn from the documents can stand up to independent inferences and reliability involves data that is constant during the measuring process (Krippendorff, 2004). In order to achieve intercoder reliability and agreement: the coders must be selected from a population in which he/she is equally capable of being selected; each coder works independently; and that they utilize the same coding instructions (Krippendorff, 2004: 215-217).

To insure that the coding scheme is free from ambiguity for this study, once the coding scheme was developed it was tested by two independent coders. In keeping with Krippendorff's rules above, the two independent coders were selected from a population of graduate students; they each independently coded one hearing; and they were provided with the same coding instructions. Though the majority of the coding was straightforward for this study was very straightforward, the coding of the testimony could have been considered subjective; therefore two independent coders coded the same hearing to insure the level of agreement of the coding scheme. The results are provided below:

Hearing Characteristics:	**Coder 1**	**Coder 2**
Date of Hearing	7/21/1999	7/21/1999
Name of Committee	Subcommittee on Health & Environment	Subcommittee on Health & Environment
Name of Chairperson	Tom Bliley	Tom Bliley
State of Chairperson	VA	VA
Presenter 1		
Name of Presenter	Nancy Lee	Nancy Lee
Gender of Presenter	Female	Female
Name of Organization	CDC	CDC

Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	0	0
Length of Presentation	121	121
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment 6-Prevention	4	4
Presenter 2		
Name of Presenter	Fran Visco	Fran Visco
Gender of Presenter	Female	Female
Name of Organization	National Breast Cancer	National Breast Cancer
Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	1	1
Length of Presentation	91	91
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment 6-Prevention	4	4
Presenter 3		
Name of Presenter	Susan Braun	Susan Braun
Gender of Presenter	Female	Female
Name of Organization	Susan G. Komen	Susan G. Komen
Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	1	1
Length of Presentation	98	98
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment	4	4

6-Prevention		
Presenter 4		
Name of Presenter	Carloyn Tapp	Carloyn Tapp
Gender of Presenter	Female	Female
Name of Organization	Women of Color B.C	Women of Color B.C
Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	1	1
Length of Presentation	64	64
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment 6-Prevention	4	4
Presenter 5		
Name of Presenter	Stanley Klausner	Stanley Klausner
Gender of Presenter	Male	Male
Name of Organization	N/A	N/A
Type of Organization: 0- Government 1-NGO 2-Corporate/Industry 3-Advocacy	N/A	3
Length of Presentation	88	88
Topic/Content of Presentation: 1-Genetics 2-Lifestyle Choices 3-Screening Methods 4-Medical Treatment 5-Environment 6-Prevention	1	4 & 1

The hearing that was coded consisted of five testimonies and the two independent coders coded all but one of the testimonies the same. Coder 1 rated the topic of the last testimony to be Genetics and Coder 2 rated the last testimony to be about Genetics and Medical Treatments. There was at least 100% agreement between the two independent coders for all of the testimony but one, which was not even a full disagreement. The

overall agreement between the two coders was 95%. This coding scheme was also reviewed and approved by the Dissertation committee. Once the coding sheet was validated using these two methods, it was used for this study.

Data Analysis

The Atlas.ti software package was used to facilitate the Content Analysis and to assist with identifying the predominant themes in the testimony. Atlas.ti is a tool which provides for managing, organizing and supporting qualitative data. It is considered to be a powerful tool for qualitative analysis of large bodies of textual data. It offers a variety of tools for coding of rich text and Word material and it can convert quantitative data to SPSS™ and coding tables to export into Excel™.

This software package provided the means to define the coding scheme and ability to analyze the hearings based on this coding scheme. Once the testimony from each of the hearings was coded to identify the predominant themes, the total number of lines along with data about each of the presenters and organizations which testified was recorded in an Excel spreadsheet. These spreadsheets were used to develop tables which assisted with the descriptive analysis.

The data was also converted into SPSS version 16 and additional descriptive analysis was completed and the One Way Analysis of Variance (One Way ANOVA) and other statistical tests were used to test for significance for all three hypotheses.

CHAPTER 4: RESULTS & DISCUSSION

Overview

Chapters one through three have provided an overview about the etiology of breast cancer; the current research funding policies for this disease; an explanation of the two main discourses and the associated six advocacy coalitions that explain how and why these research funding policies might be determined; the theoretical framework; and a summary of the major findings and gaps. Chapter three also presented the methodology that was used; the research needs; research design; sampling rationale, data collection; and data processing and analysis. The purpose of this chapter is to describe and discuss the results from the content analysis of the Congressional hearings. This chapter includes four sections: the purpose of the study; hypotheses; data analysis; and summary of results.

Purpose of the Study

There are many studies which have identified environmental carcinogens as potential causative agents for breast cancer; but none of the studies has explained why research funding polices for breast cancer do not focus on funding research activities for the environmental causes of breast cancer. The literature review from Chapter two revealed that there seems to be a disparity between the existing research funding priorities and the causes of breast cancer and the need for research into how and why this disparity exists. In order to determine how and why research funding policies for breast cancer are formulated and if in fact these policies systematically exclude funding for the role of environmental carcinogens on breast cancer causation, this study applied the

theoretical arguments from sociology and utilized the Advocacy Coalition Framework (ACF) to conduct a thorough policy analysis of research funding policies for breast cancer.

This research was conducted to answer several questions:

- How the research funds are being spent and why certain causes receive more research funding while other causes are not funded?
- Why there is a funding mismatch between the causes and research activities being funded?
- Are there variations in the levels of advocacy for the different causes?
- Do these variations impact research funding levels?
- Are the levels of advocacy determining research priorities for funding?

In order to best answer the above questions, the hypotheses must be addressed individually. The three hypotheses for this study are reiterated in the next section and they will be addressed first by the qualitative analysis of each of the Congressional hearings, followed by the quantitative analysis to determine if in fact the data supports the null or the alternative hypotheses.

Hypotheses

The first hypothesis for this study was that research funding policies for breast cancer are driven by a policy process that is dominated by a combination of discursive coalitions that marginalize advocacy for research on the environmental causes of breast cancer.

* Various agencies and actors join together to form the six advocacy coalitions which stem from the two main discourses or discursive frames (conventional or alternative).

The null hypothesis is: Ho- All discursive coalitions have equal participation in the hearing process.

The alternative hypothesis: Ha- The discursive coalition advocating research into the environmental causes of breast cancer is marginalized in the hearing process.

The second hypothesis for this study was that the higher level of advocacy for non-environmental causes of breast cancer results in higher funding level for non-environmental causes of breast cancer over environmental causes.

The null hypothesis is: Ho- Research Funding Priorities are not related the different levels of discursive coalition participation in the hearing process.

The alternative hypothesis: Ha- Research Funding Priorities are related to the different levels of discursive coalition participation in the hearing process.

The third hypothesis for this study was that the economic interests of the presenter impacts the nature if the testimony for or against research funding on the environmental causes of breast cancer.

The null hypothesis is: Ho- The economic interests of the presenter does not impact the nature of the testimony.

The alternative hypothesis: Ha- The economic interests of the presenter do impact the nature of the testimony.

Qualitative Analysis of Each Hearing

As mentioned in Chapter three, the breast cancer movement came into governmental prominence in 1990 with the passage of the Breast and Cervical Cancer Mortality Prevention Act. Since that time there have been many Congressional hearings devoted to the topic of breast cancer. These hearings have covered issues associated with insurance coverage for certain procedures, the need for a breast cancer stamp, and funding for research activities. Due to the fact that this study focused only on funding policies for research activities, the sampling criteria for inclusion in this study were: Congressional hearings which addressed research funding and activities for breast cancer. A modified LexisNexis search based on this criterion identified 8 such Congressional hearings that were available in print; hence the sample size for this study consisted of these Congressional hearings. A coding sheet was developed to be utilized for the Content Analysis and tested by two independent coders to ensure validity of the coding sheet. The coding sheet was adjusted to also include feedback from the dissertation committee. The results for each of the 8 hearings are as follows.

Hearing # 1: *The Role of Early Detection and Complementary and Alternative Medicine in Women's Cancers*

This hearing was held on August 10, 1999 before the Committee on Government Reform. The hearing was held to determine if there were alternative medicines for use in treating cancers, including breast cancer and funding for appropriate research activities. The qualitative analysis determined that the predominant coalitions and discourses

represented were the screening methods and medical treatment. Nine people were invited to testify, five of which were women and Table P-2 below summarizes the coding results of the testimony:

Table P-2

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title/ Position	Education	Gender	Organization	Organization Type	Discourse/Advocacy Coalition
Priscilla Mack	Executive Co-Chair	N/A	Female	Susan G. Koman	1	3 , 4
Michio Kushi	N/A	N/A	Male	Kushi Institute	1	2
Carol Zurycki	N/A		Female	Advocate	3	5, 6
Lee Garden	N/A	PhD	Female	Advocate	3	6
Linda L Bedell Logan	President /CEO		Female	Solutions Integrative Medicine	2	4 ,6
James Gordon	Founder	MD	Male	Center for Mind Body Medicine	3	2
Susan Silver	N/A	N/A	Female	George Washington University	3	2 ,3
Dan Beilin	Researcher	PhD, MD	Male	UCLA	3	3
Edward Trimble	Head of Surgery	MD	Male	NCI	0	1 ,3,4

Hearing # 2: *Making Sense of the Mammography Controversy: What Women Need to Know*

This hearing was held on February 28, 2002 in front of the Subcommittee on Public Health of the Committee on Health, Education, Labor, and Pensions. Six people were invited to testify and only two were women. The predominant themes of the coalitions which testified and the discourses represented were medical treatments and screening methods. Table P-3 below summarizes the coding results of the testimony:

Table P-3

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title or Position	Education	Gender	Organization	Organization Type	Discourse/ Advocacy Coalition
Andrew Von Eschenbach	Director	MD	Male	NCI	0	3, 4
Donald Berry	Chairman	MD	Male	Anderson Cancer Center	2	3,4
Harman Eyre	Chief Medical Officer	MD	Male	ACS	1	3, 4
Fran Visco	President	Lawyer	Female	National Breast Cancer Coalition	1	3 ,4 , 5
Carolyn Runowicz	Vice-Chairman	MD	Female	St.Lukes Roosevelt Hospital	2	3 ,4
Lasalle D. Leffall	Chairman-Elect	MD, FACS	Male	Susan G.Komen	1	3,4

Hearing # 3: *Breast and Cervical Cancer Federally Funded Screening Programs*

This hearing was held on July 21, 1999 in front of the Subcommittee on Health and Environment of the Committee on Commerce. Five people were invited to testify, of which four were women. The predominant themes of the advocacy coalitions represented at this hearing were screening methods and medical treatment and Table P-4 below summarizes the coding results of the testimony:

Table P-4

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title or Position	Education	Gender	Organization	Organization Type	Discourse/ Advocacy Coalition
Nancy Lee	Director-Cancer Prevention	MD	Female	CDC	0	3,4
Fran Visco	President	Lawyer	Female	National Breast Cancer Coalition	1	3 , 4, 6
Susan Brawn	President & CEO	N/A	Female	Susan G.Komen	1	3 , 4

Carolyn Tapp	President	N/A	Female	Women of Color Breast Cancer	3	4
Stanley Klausner	Surgeon/Director	MD	Male	Brookhaven Memorial Hospital	3	3 , 4

Hearing # 4: *Cancer Clusters in Long Island, NY*

This hearing was held on June 11, 2001 in front of the Committee on Environment and Public Works. Twelve people were invited to testify, seven were women, and the predominant theme of this hearing was about the environmental causes of breast cancer and the dominant advocacy coalition was the environment. In fact this hearing was convened to support the creation the Breast Cancer and Environmental Research Act. This Act would have established research activities that were geared towards gaining better understanding about what links between the environment and breast cancer may exist, and would have authorized funding to the National Institute of Environmental Health Sciences (NIEHS) to establish multidisciplinary, multi-institutional research centers to study these potential links. Table P-5 summarizes the coding results of the testimony:

Table P-5

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title or Position	Education	Gender	Organization	Organization Type	Discourse/ Advocacy Coalition
Gail Frankel	Field Coordinator	N/A	Female	National Breast Cancer Coalition	3	5
Marlie Gamman	Associate Professor	PhD	Female	SPH- Chapel Hill NC	3	5
Lynn Glodman	Professor	MD, MPH	Female	Johns Hopkins SPH	3	5
Richard Jackson	Director	MD, MPH	Male	CDC- NCEH	0	5
Amy Juchatz	Health Program Analyst	N/A	Female	Suffolk County Health	0	5
Phil Landrigan	Professor/ Chair	MD, MSC	Male	MtSinia Sch.Medi	3	5
Karen Joy Miller	Founder/ President	N/A	Female	NY Breast Cancer Action Coalition	3	5,6
Ruby Seni	Professor	PhD	Female	Mailman SPH- Columbia	3	5
Tim Tobin	Parent	N/A	Male	N/A	3	5
Randall Todd	State Epidimiogist	MD	Male	Nevada State Health	0	5
Deborah Winn	Acting Associate Director	PhD	Female	NCI	0	1, 5
Samual Wilson	Deputy Director	MD	Male	National Institute of Environmental Health	0	1,2,5

Hearing # 5: *Tamoxifen and Breast Cancer*

This hearing was held in 1998 in front of the Senate Committee on Appropriations. Six people were invited to testify, only two were women, and the predominant advocacy coalitions that testified were genetics, screening, and medical treatments. Table P-6 below summarizes the coding results of the testimony:

Table P-6

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title or Position	Education	Gender	Organization	Organization Type	Discourse/ Advocacy Coalition
Harold Varmus	Director	MD	Male	NIH	0	2,4
Norman Wolmark	Chairman	MD	Male	National Surgical (NSABP)-NCI	1	4
Richard Klausner	Director	MD	Male	NCI	0	1, 4
Helen Wilson	Clinical Trial Manager	RN	Female	Merk	3- Pharmaceutical	4
Cynthia Pearson	Executive Director		Female	National Women's Health Network	3	6
Bernard Fisher	Chairman	MD	Male	National Surgical (NSABP)-NCI	3	1,3,4

Hearing # 6: *Women and Cancer: Where Are We in Prevention, Early Detection and Treatment of Gynecologic Cancers?*

This hearing was held on September 7, 2005 in front of the Subcommittee on Criminal Justice, Drug Policy, and Human Resources of the Committee on Government Reform. This hearing focused on determining how early detection and medical treatments can impact cancers, specifically breast cancer. The predominant advocacy coalitions that testified were genetics, lifestyle choices, screening methods and medical treatment. Seven people were invited to testify, three were women, and Table P-7 below summarizes the coding results of the testimony:

Table P-7

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title or Position	Education	Gender	Organization	Organization Type	Discourse/ Advocacy Coalition
Beth Kartan	President	MD	Female	Society of Gynecologic Oncologists	3	1,2,4,6
Mark Jay Rosenfeld	Scientist/Researcher	MD	Male	Research/Advocacy	3	3
Sheryl Silver	President/ Johanna's Law	N/A	Female	Foundation	1	3
Kolleen Stacey	N/A	N/A	Female	Survivor	3	3,4,6
Edward Trimble	Head of Surgery	MD	Male	NCI	0	3, 4
Edward Thompson	Chief of Public Health Practice	MD, MPH	Male	CDC	0	2,3,4
Richard Pazer	Director	MD	Male	FDA	0	4

Hearing # 7: *Mammography*

This hearing was held on February 5, 1997 in front Senate Committee on Appropriations. The hearing was convened to review the role of mammography programs as a means for reducing morbidity and mortality from breast cancer. Eight people were invited to testify, four were women, and Table P-8 below summarizes the coding results of the testimony:

Table P-8

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title or Position	Education	Gender	Organization	Organization Type	Discourse/ Advocacy Coalition
Richard Klausner	Director	MD	Male	NCI	0	3
Susan Blumenthal	Deputy Asst. Secretary	MD, MPA	Female	US Surgeon General	0	3
Fran Visco	President	Lawyer	Female	National Breast Cancer Coalition	1	3, 6
Susan Brawn	President	N/A	Female	Susan G.Komen	1	3
Diana Rowden	Chair	N/A	Female	Susan G.Komen	1	3
Ann M. Leitch	Assosciate Professor	MD	Female	University of Texas Med. Sch. ACS	3	3, 4
Barbara Monsees	Assosciate Professor	MD	Female	St.Louis Med. Sch.- ACS	3	3
David G. Hoel	Professor/Chair	PhD	Male	Hollings Cancer Center- NIH	3	3, 4

Hearing # 8: *Breast Cancer Research and Development*

This hearing was held on May 9, 2001 in front Senate Committee on Appropriations. The hearing was convened to determine the current research activities funded for breast cancer. Eight people were invited to testify, four were women, and Table P-9 below summarizes the coding results of the testimony:

Table P-9

The numbers in the Tables represent:
Type of Organization: 0- Government, 1-NGO, 2-Corporate/Industry, 3-Advocacy;
Discourse/Advocacy Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Presenter	Title or Position	Education	Gender	Organization	Organization Type	Discourse/ Advocacy Coalition
Richard Klausner	Director	MD	Male	NCI	0	1,,2, 3 ,4
James Marks	Director	MD, MPH	Male	CDC	0	3, 4
Nancy Brinker	Chairman	N/A	Female	Susan G.Komen	1	3, 4
Christine Carpenter	Member	Masters	Female	National Breast Cancer Coalition	1	3, 4
Peri Giplin	Actress		Female	National Breast Cancer Coalition	1	3, 4

Lasalle D. Leffall	Chairman-Elect	MD, FACS	Male	Susan G.Komen	1	3, 4
John Seffrin	CEO	MD	Male	ACS	1	3, 4
Fran Visco	President	Lawyer	Female	National Breast Cancer Coalition	1	3,4,5,6

Quantitative Analysis of the Hearing Data

The qualitative analysis has provided very descriptive and detailed information for each of the hearings. The analysis has provided very specific information about the agencies and actors that testified and the discourse advocacy coalitions they represented during their testimony; along with information about the gender and educational background for each of the presenters/actors. Though this qualitative analysis has provided very rich and detailed information about the hearings, quantitative analysis has to be conducted to test for significance and to determine if the qualitative analysis mirrors the quantitative analysis.

In order to perform the appropriate quantitative analysis and accurately test each of the hypotheses, the data for the following variables had to be collapsed into binary variables: discourse, presenter's interest, and research funding. These three variables originally had values that were too specific leading to very small "n's" and therefore any statistically significant value would have to be interpreted with caution. For these reasons, it was decided that the discourse variable (advocacy coalition) would be separated into two categories: individual (the internal) and the environment (external).

The original six advocacy coalition categories were collapsed into- 1= Individual- which included testimony about Genetics, Lifestyle Choices, Screening Methods, Medical Treatments, and Prevention; and 2= Environment- which included testimony about the environmental carcinogens. The presenter's interest variable was collapsed into: 1=economic interest, the presenter/actor or presenter's agencies seeking funding; and 2= no economic interest, the presenter/actor not seeking funding. The research funding variable was collapsed into 1=funded research activities and 2= not funded.

Descriptive Analysis

A total of 8 hearings were coded for this study. Sixty-one testimonies were presented during these hearings and the number of testimonies per hearing ranged from 5 presenters in Hearing # 3 to 12 presenters in Hearing # 4. Fifty-three unique individuals presented these 61 testimonies, with several individuals testifying at more than one hearing. Dr. Lasalle D.Leffall and Susan Brawn both representing, the Susan G. Komen Foundation, testified at two different hearings; Dr. Edward Trimball and Dr.Richard Klausner, both representing the NCI, testified a total of five times; and Fran Visco, an attorney and the founder of the National Breast Cancer Coalition, testified four times. Of the 61 testimonies, 42.6% consisted of testimony regarding a single advocacy coalition discourse; 41.0 % testified for two advocacy coalitions, 11.5% presented three, and 4.9% testimonies included four advocacy coalitions in their testimony.

There were slightly more female presenters than male (54.7% vs. 45.3%). There was no significant difference in the number of lines or percentage of lines testimony by gender. The educational background of the presenters consisted of 49.1 % MDs, 11.3%

were PhDs, and 32.1% did not have a graduate or professional degree. These presenters were survivors, film actors, and parents of survivors. The average percentage of lines of testimony by education was also not significantly different.

Of all of the testimony presented, nearly two-thirds advocated for the following coalitions: screening methods, medical treatment, and environment. When the hearing that was dedicated to environmental issues (hearing # 4) was removed from the analysis, the predominant coalitions represented at all of the hearings were the Screening Methods and Medical Treatment coalitions. More than half of the presenters were associated with organizations that represent medical and research institutions, universities, and foundations which fundraise for breast cancer. The main organization types represented were: NGOs (43.4 %) which receive funding from the government and donations; the government agencies which distribute grant funds for research (26.4%); and advocacy groups (24.5%), which consisted of survivors or have family members impacted by the disease. There were a few presenters who represented business and industry, mainly the pharmaceutical companies and cancer treatment facilities.

Hypothesis Testing

Due to the fact that this study has a small sample size, small sample statistics were utilized. The statistical analysis consisted of analysis of variance (One Way ANOVA), Independent t-tests, and cross tabulations. The first hypothesis for this study was that research funding policies for breast cancer are driven by a policy process that is dominated by a combination of discursive coalitions that marginalize advocacy for research on the environmental causes of breast cancer.

Figure P-7 is a graph depicting the coalition and the total number of lines of testimony by coalition for all 8 hearings. The graph has two bars, with the blue bar representing the analysis with the Environmental hearing included and the burgundy bar representing the analysis with the Environmental hearing (hearing # 4) excluded. The Screening Methods and Medical Treatment coalitions had the most amount of testimony, regardless of whether the Environmental hearing was included or excluded.

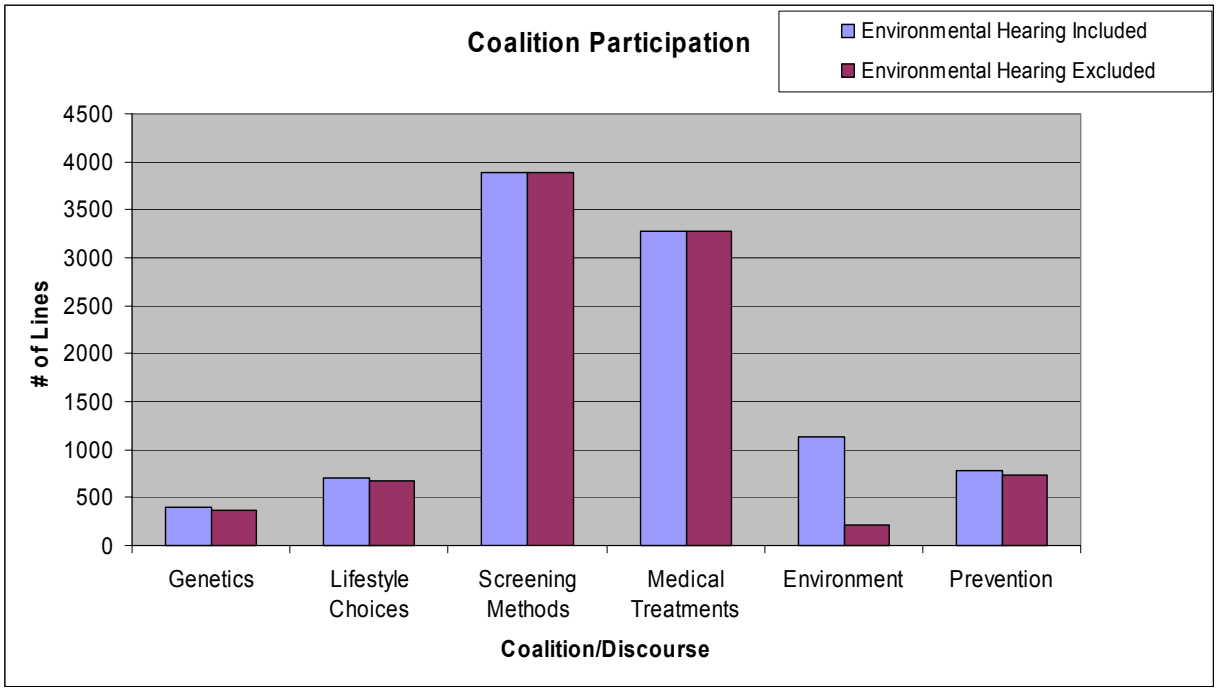


Figure P-7: Coalition Participation for all Congressional Hearings

Though the descriptive analysis regarding the percent of testimony being higher for Screening Methods and Medical Treatments may suggest the marginalization of the other advocacy coalitions, the statistical analysis showed no significant difference in the

percent of lines of testimony by advocacy coalition/discourse, even with the Environmental hearing removed, hence the alternative hypothesis Ha- "The discursive coalition advocating research into the environmental causes of breast cancer is marginalized in the hearing process", must be rejected and the null hypothesis is: Ho- "All discursive coalitions have equal participation in the hearing process", would be accepted.

The second hypothesis for this study was that the higher level of advocacy for non-environmental causes of breast cancer results in higher funding level for non-environmental causes of breast cancer over environmental causes. Table P-10 represents the hearing, the year of the hearing, the dominant testimony based on the advocacy coalition with the most number of lines and the percentage of testimony devoted to the advocacy coalition, and the funded research activities from the appropriations for the NCI budget for the fiscal year following the hearing and the ACS budget for research activities for this same time period.

Table P-10

The numbers in the Tables represent:
Discourse/Coalition of Presentation: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention
Research Activities Funded: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Hearing #	Year of Hearing	Dominant Testimony Advocacy Coalitions		Discourse of Funded Research Activities
		# of Lines	% (# of lines for discourse/total # of lines)	
1	1999	1- 111**; 2 -428 lines**; 3-244.5 lines; 4-285; 5-76 lines; 6-340 lines	1- 7.1%**; 2 -27.3%**; 3-20.8%; 4-18.2%; 5-4.8%; 6-21.7%	1, 2, 3, 4
2	2002	**3 - 850 lines**; 4 -849 lines; 5- 99 lines	**3-47.3%**; 4 -47.2%; 5-5.5%	1, 2, 3, 4
3	1999	3- 451 lines; **4-562 lines**; 6- 95 lines	3-40.7%; **4-50.7%**; 6-8.6%	1, 2, 3, 4
4	2001	1- 27 lines; 2-29 lines; **5- 848 lines**; 6-51 lines	1- 2.6%; 2-2.7%s; **5-80.3%**; 6-4.8%	1, 2, 3, 4
5	1998	1 -103 lines; 2 -24 lines; 3- 17 lines; **4-542 lines**; 6-150 lines	1 -12.4%; 2 -2.9%; 3-2 %; **4-65%**; 6-18%	1, 2, 3, 4
6	2005	1 -34 lines; 2 -94 lines; **3- 267 lines**; 4-227 lines; 6-57 lines	1 -5%; 2 -13.8%; **3-39.3%,** 4- 33.4%; 6-8.4%	1, 2, 3, 4
7	1997	**3 - 1330 lines**; 4 -172 lines; 6- 61 lines	**3 – 85.1%**; 4 -11%; 6-4%	1, 2, 3, 4
8	2001	1 -123 lines; 2 -123 lines; 3- 643 lines; **4-644 lines**; 5- 32 lines; 6-57 lines	1 -7.7%; 2 -7.7%; 3-40%; **4- 40.1%**; 5-2%; 6-3.5%	1, 2, 3, 4

Based on this table, it can be seen that for all but one of the hearings, the advocacy coalitions which testified and had the greater number of lines or higher percentage of testimony (in bold text) received funding for research activities. Hearing # 4 is the only exception to this finding, though the Environmental Advocacy Coalition had the most lines of testimony, there was no impact on the funding for research activities. A review of the fiscal year budgets for NCI and ACS revealed that though the overall funding for research activities for breast cancer has increased over the years; there have been no changes in the coalitions being funded for research activities. The bulk of the funding continues to support research activities that are represented by the Genetics, Lifestyle Choices, Screening Methods, and Medical Treatments.

The statistical analysis for hypothesis two showed no statistically significant difference in the percent of lines of testimony and research funding ($t=1.75$, $p=0.082$), therefore the null hypothesis "research funding priorities are not related to the different levels of discursive coalition participation in the hearing process." would be accepted.

The third hypothesis for this study stated that the economic interests of the presenter impacts the nature if the testimony for or against research funding on the environmental causes of breast cancer. This hypothesis speaks to the notion that research funding decisions are based on profit and that the coalitions which testify at the hearings are driven by economic interests rather than science. The table P-11 provides the results from the content analysis and gives insight into the presenter, the organization, the mission of the organization, the advocacy coalition, and the research activities the organization supports.

Table P-11

The numbers in the Tables represent: Presenter's Coalition of Interest: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention
Research Activities Funded: 1-Genetics, 2-Lifestyle Choices, 3-Screening Methods, 4-Medical Treatment, 5-Environment, 6-Prevention

Hearing # 1				
Presenter	**Organization**	**Organization Mission**	**Presenter's Interests**	**Research Activities Funded**
Priscilla Mack	Susan G. Komen	We are dedicated to curing breast cancer at every stage - from the causes to the cures, to the pain and anxiety of every moment in between.	3, 4	1, 2, 3, 4
Michio Kushi	Kushi Institute	Our Mission is to teach, guide and inspire individuals towards greater personal freedom, health, happiness and peace by using the principles of Kushi Macrobiotics.	2	2
Carol Zurycki	Advocate	Not Available	5,6	N/A
Lee Garden	Advocate	Not Available	6	N/A
Linda L Bedell Logan	Solutions Integrative Medicine	Not Available	4,6	4
James Gordon	Center for Mind Body Medicine	Not Available	2	2
Susan Silver	George Washington University	Teaching with creativity and dedication, Healing with quality and compassion, Discovering with imagination and innovation.	2,3	1, 2, 3, 4
Dan Beilin	UCLA		3	1, 2, 3, 4
Edward Trimble	NCI	The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training	1,3,4	1, 2, 3, 4
Hearing # 2				
Presenter	**Organization**	**Organization Mission**	**Presenter's Interests**	**Research Activities Funded**
Andrew Von Eschen-bach	NCI	The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal	3,4	1, 2, 3, 4

		agency for cancer research and training		
Donald Berry	Anderson Cancer Center	Our mission is simple – to eliminate cancer. Achieving that goal begins with integrated programs in cancer treatment, clinical trials, education programs and cancer prevention.	3,4	1, 2, 3, 4
Harman Eyre	ACS	The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.	3,4	1, 2, 3, 4
Fran Visco	National Breast Cancer Coalition	To achieve our mission of ending breast cancer, we focus on the following three main goals: RESEARCH: Increasing appropriations for high-quality, peer-reviewed research and working within the scientific community on issues of importance to women with, or at risk of, breast cancer ACCESS: Increasing access for all women to high-quality treatment and care, as well as breast cancer clinical trials INFLUENCE: Increasing the influence of women living with breast cancer and other breast cancer activists in the decision-making that impacts all issues surrounding breast cancer	3,4,5,6	N/A
Carolyn Runowicz	St.Lukes Roosevelt Hospital	Established in 1871, St. Luke's-Roosevelt Hospital Center, University Hospital of Columbia University College of Physicians and Surgeons, is a 1,076-bed, full-service community and tertiary care hospital.	3,4	1, 2, 3, 4
Lasalle D. Leffall	Susan G.Komen	We are dedicated to curing breast cancer at every stage - from the causes to the cures, to the pain and anxiety of every moment in between.	3,4	1, 2, 3, 4

Hearing # 3				
Presenter	**Organization**	**Organization Mission**	**Presenter's Interests**	**Research Activities Funded**
Nancy Lee	CDC	To direct, monitor, and report on activities associated with the implementation of the Breast and Cervical Cancer Mortality Prevention Act of 1990, Public Law 101-354 and the Cancer Registries Amendment Act, Public Law 102-515.	3,4	1, 2, 3, 4
Fran Visco	National Breast Cancer Coalition	To achieve our mission of ending breast cancer, we focus on the following three main goals: RESEARCH: Increasing appropriations for high-quality, peer-reviewed research and working within the scientific community on issues of importance to women with, or at risk of, breast cancer ACCESS: Increasing access for all women to high-quality treatment and care, as well as breast cancer clinical trials INFLUENCE: Increasing the influence of women living with breast cancer and other breast cancer activists in the decision-making that impacts all issues surrounding breast cancer	3,4,5,6	N/A
Susan Brawn	Susan G.Komen	We are dedicated to curing breast cancer at every stage - from the causes to the cures, to the pain and anxiety of every moment in between.	3,4	1, 2, 3, 4
Carolyn Tapp	Women of Color Breast Cancer	Provide psychosocial for you and your loved ones; Provide crisis intervention for you and your loved ones; Provide breast health education to community members at large; Offer knowledge focused on early detection; Commit to effecting public policy; Commit to social change regarding breast health awareness; Support culturally sensitive research; Lobby on both state and federal levels for breast cancer legislation	4	2

Stanley Klausner	Brookhaven Memorial Hospital	Deliver accessible, high-quality health services in a focused caring environment while providing health advocacy for the community and people we serve.	3,4	1, 2, 3, 4
Hearing # 4				
Presenter	**Organization**	**Organization Mission**	**Presenter's Interests**	**Research Activities Funded**
Gail Frankel	National Breast Cancer Coalition	To achieve our mission of ending breast cancer, we focus on the following three main goals: RESEARCH: Increasing appropriations for high-quality, peer-reviewed research and working within the scientific community on issues of importance to women with, or at risk of, breast cancer ACCESS: Increasing access for all women to high-quality treatment and care, as well as breast cancer clinical trials INFLUENCE: Increasing the influence of women living with breast cancer and other breast cancer activists in the decision-making that impacts all issues surrounding breast cancer	5	1, 2, 3, 4
Marlie Gamman	SPH- Chapel Hill NC	The School's mission is to improve public health, promote individual well-being and eliminate health disparities	5	1, 2, 3, 4
Lynn Glodman	John's Hopkins SPH	The Johns Hopkins Bloomberg School of Public Health is dedicated to the education of a diverse group of research scientists and public health professionals, a process inseparably linked to the discovery and application of new knowledge, and through these activities, to the improvement of health and prevention of disease and disability around the world.	5	1, 2, 3, 4
Richard Jackson	CDC- National Env. Cent.	The National Center for Environmental Health plans, directs, and coordinates a national program to maintain and improve the health of the	5	1, 2, 3, 4

		American people by promoting a healthy environment and by preventing premature death and avoidable illness and disability caused by non-infectious, non-occupational environmental and related factors.		
Amy Juchatz	Suffolk County Health	The mission of the Suffolk County Department of Health Services is to assure the well-being of the community by preventing disease, promoting healthy behavior and preserving the health of our residents.	5	1, 2, 3, 4
Phil Landrigan	MtSinia Sch.Medi	Commitment to excellence in research, education, and patient care form the foundation that makes Mount Sinai School of Medicine (MSSM) in Manhattan one of the world's foremost centers for medical and scientific training.	5	1, 2, 3, 4
Karen Joy Miller	NY Breast Cancer Action Coalition	Our mission is to focus on prevention methods while actively helping those who are faced with a positive diagnosis.	5,6	N/A
Ruby Seni	Mailman SPH-Columbia	Not Available	5	N/A
Tim Tobin	N/A	Not Available	5	N/A
Randall Todd	Nevada State Health	Not Available	5	N/A
Deborah Winn	NCI	The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training	1,5	1, 2, 3, 4
Samual Wilson	National Institute of Environmental Health	The mission of the NIEHS is to reduce the burden of human illness and disability by understanding how the environment influences the development and progression of human disease.	1,2,5	1, 2, 3, 4
Hearing # 5				
Presenter	**Organization**	**Organization Mission**	**Presenter's Interests**	**Research Activities Funded**
Harold Varmus	NIH	NIH is the steward of medical and behavioral research for the	2, 4	1, 2, 3, 4

		Nation. Its mission is science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability		
Norman Wolmark	National Surgical (NSABP)- NCI	The NSABP pioneered breast cancer studies that have led to the establishment of lumpectomy plus radiation over radical mastectomy as the standard surgical treatment of breast cancer	4	2, 3, 4
Richard Klausner	NCI	The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training	1, 4	1, 2, 3, 4
Helen Wilson	Merk	The mission of Merck is to provide society with superior products and services by developing innovations and solutions that improve the quality of life and satisfy customer needs, and to provide employees with meaningful work and advancement opportunities, and investors with a superior rate of return.	4	3, 4
Cynthia Pearson	National Women's Health Network	The National Women's Health Network improves the health of all women by developing and promoting a critical analysis of health issues in order to affect policy and support consumer decision-making. The Network aspires to a health care system that is guided by social justice and reflects the needs of diverse women.	6	1, 2, 3, 4
Bernard Fisher	National Surgical (NSABP)- NCI	The NSABP pioneered breast cancer studies that have led to the establishment of lumpectomy plus radiation over radical mastectomy as the standard surgical treatment of breast cancer	1,3,4	1, 2, 3, 4

Hearing # 6				
Presenter	**Organization**	**Organization Mission**	**Presenter's Interests**	**Research Activities Funded**
Beth Kartan	Society of Gynologic Oncologists	The purpose of SGO is to improve the care of women with gynecologic cancers by encouraging research and disseminating knowledge to raise the standards of practice in the prevention and treatment of gynecologic malignancies, in cooperation with other organizations interested in women's health care, oncology and related fields.	1,2,4,6	1, 2, 3, 4
Mark Jay Rosenfeld	Research/Advocacy	Not Available	3	N/A
Sheryl Silver	Foundation	Not Available	3	N/A
Kolleen Stacey	Survivor	Not Available	3,4,6	N/A
Edward Trimble	NCI	The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training	3,4	1, 2, 3, 4
Edward Thompson	CDC	To promote health and quality of life by preventing and controlling disease, injury, and disability.	2,3,4	1, 2, 3, 4
Richard Pazer	FDA	The FDA is responsible for protecting the public health by assuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, our nation's food supply, cosmetics, and products that emit radiation. The FDA is also responsible for advancing the public health by helping to speed innovations that make medicines and foods more effective, safer, and more affordable; and helping the public get the accurate, science-based information they need to use medicines and foods to improve their health.	4	2,3,4
Hearing # 7				
Presenter	**Organization**	**Organization Mission**	**Presenter's**	**Research**

			Interests	Activities Funded
Richard Klausner	NCI	The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training	3	1, 2, 3, 4
Susan Blumen-thal	US Surgeon General	The Surgeon General serves as America's chief health educator by providing Americans the best scientific information available on how to improve their health and reduce the risk of illness and injury.	3	1, 2, 3, 4
Fran Visco	National Breast Cancer Coalition	To achieve our mission of ending breast cancer, we focus on the following three main goals: RESEARCH: Increasing appropriations for high-quality, peer-reviewed research and working within the scientific community on issues of importance to women with, or at risk of, breast cancer ACCESS: Increasing access for all women to high-quality treatment and care, as well as breast cancer clinical trials INFLUENCE: Increasing the influence of women living with breast cancer and other breast cancer activists in the decision-making that impacts all issues surrounding breast cancer	3,6	N/A
Susan Brawn	Susan G.Komen	We are dedicated to curing breast cancer at every stage - from the causes to the cures, to the pain and anxiety of every moment in between.	3	1, 2, 3, 4
Diana Rowden	Susan G.Komen	We are dedicated to curing breast cancer at every stage - from the causes to the cures, to the pain and anxiety of every moment in between.	3	1, 2, 3, 4
Ann M. Leitch	University of Texas Med. Sch. ACS	Not Available	3,4	1, 2, 3, 4
Barbara Monsees	St.Louis Med. Sch.- ACS	Not Available	3	1, 2, 3, 4
David G. Hoel	Hollings Cancer Center- NIH	Not Available	3,4	1, 2, 3, 4

Hearing # 8				
Presenter	**Organization**	**Organization Mission**	**Presenter's Interests**	**Research Activities Funded**
Richard Klausner	NCI	The NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training	1,2, more 3,4	1, 2, 3, 4
James Marks	CDC	To promote health and quality of life by preventing and controlling disease, injury, and disability.	3, 4	1, 2, 3, 4
Nancy Brinker	Susan G.Komen	We are dedicated to curing breast cancer at every stage - from the causes to the cures, to the pain and anxiety of every moment in between.	3,4	1, 2, 3, 4
Christine Carpenter	National Breast Cancer Coalition	To achieve our mission of ending breast cancer, we focus on the following three main goals: RESEARCH: Increasing appropriations for high-quality, peer-reviewed research and working within the scientific community on issues of importance to women with, or at risk of, breast cancer ACCESS: Increasing access for all women to high-quality treatment and care, as well as breast cancer clinical trials INFLUENCE: Increasing the influence of women living with breast cancer and other breast cancer activists in the decision-making that impacts all issues surrounding breast cancer	3,4	1, 2, 3, 4
Peri Giplin	National Breast Cancer Coalition	To achieve our mission of ending breast cancer, we focus on the following three main goals: RESEARCH: Increasing appropriations for high-quality, peer-reviewed research and working within the scientific community on issues of importance to women with, or at risk of, breast cancer ACCESS: Increasing access for all women to high-quality treatment and care, as well as	3, 4	N/A

		breast cancer clinical trials INFLUENCE: Increasing the influence of women living with breast cancer and other breast cancer activists in the decision-making that impacts all issues surrounding breast cancer		
Lasalle D. Leffall	Susan G.Komen	We are dedicated to curing breast cancer at every stage - from the causes to the cures, to the pain and anxiety of every moment in between.	3,4	1, 2, 3, 4
John Seffrin	ACS	The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.	3, 4	1, 2, 3, 4
Fran Visco	National Breast Cancer Coalition	To achieve our mission of ending breast cancer, we focus on the following three main goals: RESEARCH: Increasing appropriations for high-quality, peer-reviewed research and working within the scientific community on issues of importance to women with, or at risk of, breast cancer ACCESS: Increasing access for all women to high-quality treatment and care, as well as breast cancer clinical trials INFLUENCE: Increasing the influence of women living with breast cancer and other breast cancer activists in the decision-making that impacts all issues surrounding breast cancer	3,4,5,6	N/A

Based on this table the interest of the presenter reflects the advocacy coalition of the organization which the presenter represents. The mission statement of each of these organizations reinforces the advocacy that the organization and/or presenter support and the research funding activities also reflect the mission and the coalition of the presenter and the organization. For example, Bernard Fisher of the NSABP Foundation, which supports the research for better medical treatments, testified for funding research activities that focus on Genetics, Screening Methods, and Medical Treatments during the Congressional hearings. Which then lead to appropriations to NCI for funding these research activities and NCI provided grants to the NSABP Foundation for research activities which specifically deal with Genetics, Screening Methods and Medical Treatments.

Most of the organizations which testified were organizations that receive funding for research from the NCI, other government agencies, and ACS. These organizations in turn testified in favor of the same research activities which lead to a reinforcing loop from the funding agencies to the researchers, who in turn testify in favor of the funding agencies and the continuation of the same or similar research activities.

Also, the majority of the presenter's seem to provide testimony related to their individual interests or the interests of the organization they represented. Though this type of testimony may help their continued research funding, it does pose a conflict of interest, because the presenters are biased by their own interests and not science. These conflicts of interests are evident based on the presenter's interests, the organization's mission and the research activities funded.

The statistical analysis revealed that the average percent of lines of testimony by the presenters' interests was not significant. Therefore the "null hypothesis: the economic interests of the presenter do not impact the nature of the testimony" would be accepted and alternative hypothesis: "the economic interests of the presenter do impact the nature of the testimony" would be rejected.

Summary

The combined use of qualitative and quantitative analysis provided both a specific and detailed view of the data and also allowed for an opportunity to adequately test each hypothesis. Though the qualitative analysis suggested that all of the alternative hypotheses may be accepted, the quantitative analysis revealed that though there was a difference in testimony, this difference was not statistically significant for Hypotheses 1, 2 and 3. Table P-12 summarizes the quatantative analysis:

Table P-12

Item	Test	Statistic	p Value	Significance
Gender	Independent T-Test	t= -0.534	0.594	No
Education	ANOVA	F=0.168	0.973	No
Hypothesis 1	Independent T-Test	t= 0.582	0.562	No
Hypothesis 2	Independent T-Test	t= 1.75	0.082	No
Hypothesis 3	Independent T-Test	t= -0.136	0.892	No

CHAPTER 5: CONCLUSION

Overview

Chapters one through four have provided an overview about the issues associated with the funding disparities between the actual causes of breast cancer and the research activities that are funded. The ground work for this study, including the research gaps and research objectives were outlined; along with the methodology to be used and the results from the research. The purpose of this Chapter is to provide a summary of this study; present a discussion and potential conclusions from the results; identify the limitations of this study; and present the significance and future research implications of this study.

Summary of the Study

This study aimed to increase the understanding of how and why breast cancer research funding policies include or exclude funding for certain risk factors over others. The literature points to three specific triggers for breast cancer causation: genetics, life style choices, and multiple carcinogens in the environment. Despite the existence of this literature which shows that 70% of breast cancer cases may be linked to the environmental carcinogens (Breast Cancer Action, 2006), there is little to no funding for research activities which focus on role of the environmental carcinogens on breast cancer incidence; this study was conducted to help determine how the research funds are being spent and why certain causes receive more research funding and other causes are not funded.

As mentioned in Chapter two the literature suggests that there seem to be two main discourses which attempt to explain how and why research funding policies for breast cancer research activities are determined. The conventional discourse stems from the National Cancer Institute (NCI) and American Cancer Society (ACS). This discourse explains that the research funding policies need to focus research activities around the first two risk factors, genetics and lifestyle choices, based on the following reasons: the increase in breast cancer can be attributed to women living longer and improved screening methods; medical treatments save lives and prevention techniques are not really available; it is difficult to impact the lifestyles of women; and it is difficult to study the effects of the environment and conclusively pinpoint how the environmental carcinogens cause breast cancer (NCI, 2006; ACS, 2006).

The alternative discourse disagrees with these reasons and explains that the research funding policies systematically exclude funding for the role of environmental carcinogens because of the following reasons: the "ruling class" of agencies (the "Cancer Establishment" and "Cancer Industry") which determine the research priorities are led by individuals with conflicts of interest; these conflicts of interest include companies that sponsor Breast Cancer Awareness month and who also own the chemical companies which produce herbicides that are linked to breast cancer incidence (Epstein & Steinmen, 1997); powerful corporate actors, such as the pharmaceutical companies, promote research funding policies for medical treatment and exclude funding for the environmental causes because of profit; and that the existing research funding policies for new screening and medical treatments are more profitable than mitigation of environmental carcinogens which may lead to prevention (Moss, 2002).

The conventional and alternative discourses unite various agencies and actors to form six advocacy coalitions which compete during Congressional hearings to set research funding policies. As mentioned earlier, the actors or agencies who represent these discourses share similar core beliefs about what the research funding policies for breast cancer should be. These agencies are separated into the six coalitions, which represent the potential funding priorities based on the three causes which have been linked to breast cancer: genetics, life style choices, and environmental carcinogens. These six coalitions are:

- Coalition A: Research into Genetics
- Coalition B: Research into Lifestyle Choices
- Coalition C: Research into Screening Methods
- Coalition D: Research into Medical Treatments
- Coalition E: Research into the Environment
- Coalition F: Research into Prevention

Coalitions A through D represent the "actors" or agencies who share core beliefs with the NCI and ACS forming the conventional discourse. Coalitions E and F represent the alternative discourse and the agencies or actors who believe that research funding policies are influenced by power and profit. The theoretical framework suggested that certain causes received research funding over other causes and that funding decisions were based on power and economics and not science. In order to best answer the above questions, three hypotheses were developed:

The first hypothesis for this study was that research funding policies for breast cancer are driven by a policy process that is dominated by a combination of discursive coalitions that marginalize advocacy for research on the environmental causes of breast cancer.

The second hypothesis for this study was that the higher level of advocacy for non-environmental causes of breast cancer results in higher funding level for non-environmental causes of breast cancer over environmental causes.

The third hypothesis for this study was that the economic interests of the presenter impacts the nature if the testimony for or against research funding on the environmental causes of breast cancer.

The Advocacy Coalition Framework was used as the theoretical model to better understand how different actors and agencies join together and form coalitions around these two main discourses and compete during the policy process to receive funding for research activities. Since the research funding policy process involves testimony in front of Congress, Congressional hearings were coded to identify the dominant advocacy coalitions testifying and which of the two discourses (conventional or alternative) were supported during the hearings and to determine if there was marginalization of certain advocacy coalitions and hence the discourses they represented versus other advocacy coalitions and the discourse they represented.

Discussion and Conclusions

A total of sixty-one testimonies were coded from eight Congressional hearings that were used in this study. Fifty-three unique individuals testified during the hearings and the qualitative and quantitative analysis of the results revealed that representatives from NCI testified at all but one of the hearings and that the Susan G. Komen foundation had representatives testify at five of the eight hearings. These results support the alternative discourse which states that the research funding priorities are set by the group of powerful organizations present during the research funding policy process. The fact that the NCI testified at all of the hearings also supports Foucault's notion of power and how knowledge and power combine to define the dominant discourse (Foucault, 1990, 1995).

In terms of breast cancer, the powerful (NCI and others, such as the Komen Foundation) testify and define the dominant discourse for the research activities should be funded for breast cancer research. Due to the fact that the actors from NCI and other agencies are in charge or in power their testimony which advocated for research activities dedicated to Screening Methods and Medical Treatments tends to form the dominant discourse for research funding activities for breast cancer. The actors from the NCI are also viewed as the scientific experts based on their titles and their affiliation with the NCI, so their testimony actually has more influence then may be the testimony from a survivor or a family member of a survivor.

The role of power and the potential influence that patriarchy could have during the breast cancer research funding policy process was discussed in Chapter 2. Women

were compared to the workers and how as the worker is excluded from participation in the policy process due to capitalism, women may be excluded from the breast cancer research funding policy process due to patriarchy (MacKinnon, 1982; Shelton and Agger, 1993; Hartsock, 1998). However, the results of this study showed that women testified at every hearing and in fact 54.7% of the people who testified at all of the hearings were women. Which leads one to question why then the nature of testimony of the advocacy coalitions represented did not change. This lack of change may be explained by the role of power; specifically Luke's third level of power which involves shaping the view of individuals so that the view is reflective of those in power (Lukes, 1974). This level of power implies that due to the fact that patriarchy is so institutionalized it influences the breast cancer research funding arena and it overshadows the gender of the presenter and the testimony is reflective of the patriarchic viewpoint about what research activities should be funded.

The educational background of the presenter also coincided with the power and market system theories which support the notions of the Cancer Establishment and Cancer Industry. Both of these notions point to the fact that those testifying have vested economic interests in the research funding policies; in fact the Cancer Establishment speaks to the idea that those in charge of the policies have conflicts of interests because they actually benefit from the funding decisions. The Scientization of Politics also supports these two notions by explaining how political and moral decisions are determined by scientific experts and the public is excluded (Habermas, 1970: 62-80). The results of this research supported these notions and theories because more than half of the individuals testifying (67.9%) were scientific experts with either a medical degree

or a doctoral degree. Their testimony was used to provide the technical evidence for research funding decisions and though survivors and family members of survivors testified, the activities funded for research did not change.

This lack of change in research activities funded and the powerful nature of the Cancer Establishment was further emphasized by the environmental hearing (hearing # 4). Twelve people testified during this hearing and they all represented the environmental advocacy coalition. This hearing was convened in 2001 to raise support for the establishment of the Breast Cancer and Environmental Research Act which would have created multidisciplinary research centers to study the role environmental carcinogens on breast cancer causation. Both experts and survivors testified at the hearing and more than half of the presenters were women. Despite the testimony, the Act never passed and no additional funds were allocated for research activities which specifically looked at the role of environmental causation on breast cancer. This lack of change could have been due to the fact that the political make-up of the government changed around this time and that the political support for this act disappeared.

The other explanation for why this Act did not pass may have had to do with the Cancer Establishment and Cancer Industry and the fact that those in power have specific economic interests to continue funding research into Medical Treatments and Screening Methods. This results support the fact that the role of the environmental carcinogens on breast cancer causation is marginalized because continued research into Medical Treatments and Screening Methods is economically beneficial to the current "ruling

class" which make the funding decisions and the research funding did not change despite the hearing.

This marginalization of the environmental advocacy coalition raises questions about the impacts associated with environmental carcinogens and the disproportionate levels of exposure experienced by minority populations as outlined by the Environmental Justice (EJ) literature and associated health impacts (Bryant, 1995; Hofricter, 2000). The EJ literature explains how minorities and low SES populations are disproportionately exposed to environmental carcinogens and that this same group is more likely to have limited access to health care. Therefore by not increasing the funding for research into the environmental causes of breast cancer, minority women, who may have greater exposure to the environmental carcinogens and access to health care issues, may be more likely to get breast cancer and die from this disease. Therefore, the lack of funding for research activities dedicated to the environmental carcinogens and breast cancer causation may be forming an unequal gradient of health care for minority and low SES populations.

Overall, the coalitions advocating for Screening Methods and Medical Treatment provided the most testimony and continued to receive the majority of funding for research activities. Despite the testimony advocating for research into the environmental causation and prevention, the actual funding for research activities did not change. This lack of change in funding levels seems to support the alternative discourse and the notions of the Cancer Establishment and Cancer Industry. The Cancer Establishment emphasizes that the current "ruling class" or power structure which consists of conflicts

of interests is driving the policy process and the Cancer Industry suggests that it is the economic interests driving the policy process. The theories of Power, Market System, and the Treadmill of Production as defined in Chapter 2 would apply based on the result of the lack of change in funding for research activities.

These social theories predicted that the advocacy coalitions with the most lines of testimony would receive the most funding. The advocacy coalitions with the greatest percent of lines of testimony were the Screening Methods and Medical Treatments and the majority of the research funding was also for these two coalitions; despite the fact that the majority of breast cancer cases can be attributed to environmental carcinogens.

Figure P-8 depicts the causes, percent of lines of testimony and the actual funding levels for research activities. The data for the causes is from the NCI and the Breast Cancer Action, the data for the percent lines of testimony is from this research study, and the data for the research activities funded is from the NCI and ACS FY07 budget. Based on the results and the available data for the causes of breast cancer, the percentage of testimony for each coalition and the research activities funded (depicted in Figure P-8), there is an obvious mismatch between the causes of breast cancer- 10 % genetics, 20% lifestyle choices, and the remaining 70% can be linked back to environmental carcinogens; the percentage lines of testimony- 38.16% Screening Methods, 32.24% Medical Treatments, 11.09% Environment, 7.74 % Prevention, 6.86% Lifestyle Choices, and 3.91% Genetics; and actual funding- 21% Medical Treatments, 20 % Genetics, 16% Screening Methods, 14% Lifestyle Choices, 9 % Prevention, and 3% Environment. Therefore, the current research activities do not address the actual cause of this disease

which would lead to decreases in the incidence rates of this disease, rather they continue to focus on research activities which only control mortality rates once the disease is discovered.

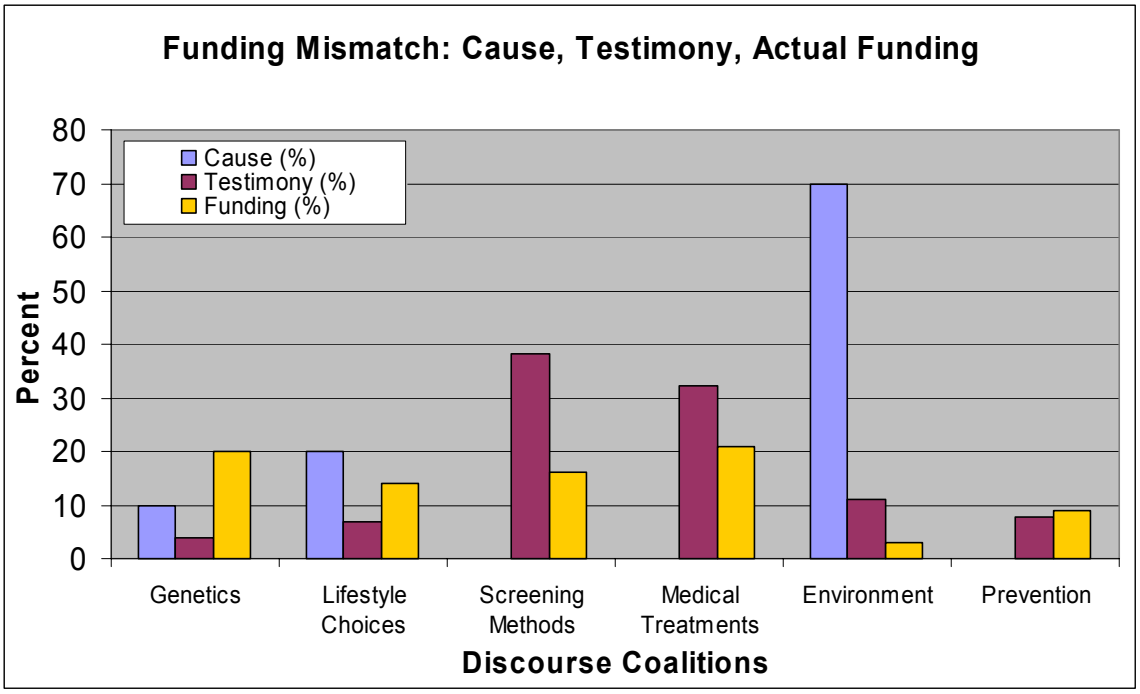


Figure P-8: Funding Mismatch: Cause, Testimony, and Actual Research Activities Funded.

Also, the fact that the funding level for research activities geared towards the role of environmental causation of breast cancer did not increase, despite the testimony provided during Hearing # 4; suggests a disparity between the cause of the disease and

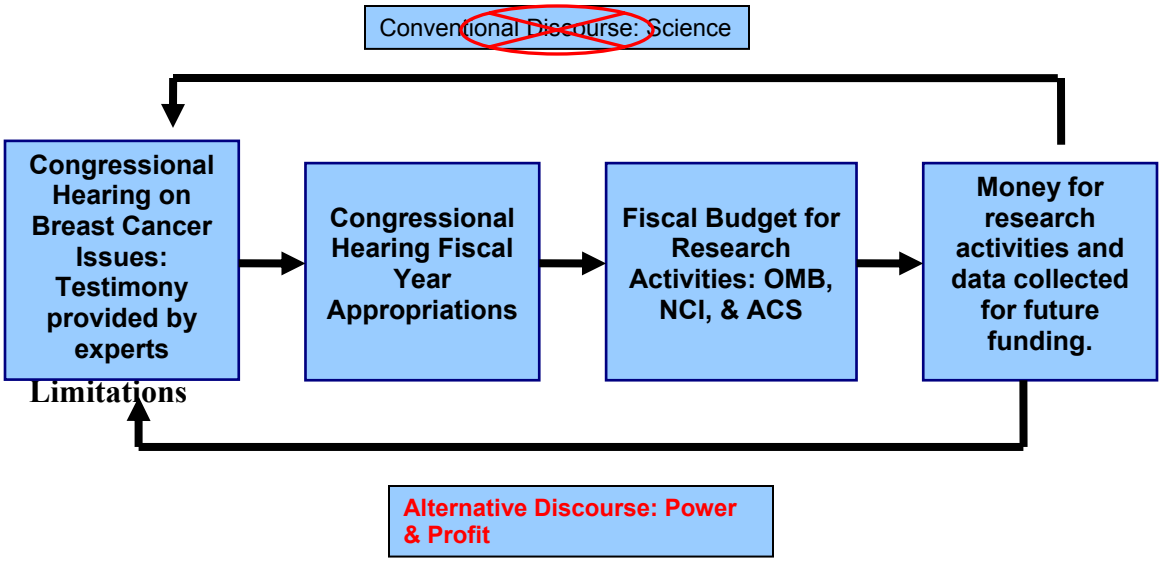
the funding being allocated towards research activities to address that cause. Overall the research funding priorities seem to represent the discursive coalitions participating during the hearing process and the fact that the Environmental Advocacy Coalition did not have an impact on the funding levels for research activities geared towards the environmental causation of breast cancer, may be reflective of the unequal distribution of power amongst the different coalitions.

In summary, this study was conducted to answer questions about research funding activities for breast cancer and to determine if and why there are funding disparities or a mismatch between the causes of breast cancer and the research activities which are funded. The analysis of the results also revealed the following information:

- All of the hearings did have testimony presented by women; though their testimony was based on their agency or organization affiliation and the discourse/coalition that the agency or organization supported.
- The coalitions for Screening Methods and Medical Treatments had the greatest amount of testimony during all of the hearings.
- The Screening Methods and Medical Treatments coalitions also received the majority of the research funding.
- Though there was an entire hearing devoted to the Environmental Advocacy Coalition and the role of the environmental carcinogens on breast cancer causation; no change was noticed in research funding for this coalition.

- Overall the research funding policies continued to fund research activities geared towards the first four coalitions: Genetics, Lifestyle Choices, Screening Methods, and Medical Treatments.
- The last two coalitions: Environment and Prevention received minimal funding for research activities; despite the fact that the Environmental coalition had an entire hearing full of testimony about the environmental impact on breast cancer causation.

Based on the analysis it may be concluded that there is a mismatch in research funding and that the policy process is driven by the alternative discourse and the conventional discourse. The model below was originally presented in Chapter 2 and it represents the two discourses and the policy process for breast cancer. The results of this study can conclude that the policy process for research funding activities for breast cancer is driven by Power and Profit, instead of Science.



This study attempted to provide an accurate picture of the policy process for breast cancer research funding policies and how and why certain causes receive funding over other causes. As with all research, several limitations were identified for this study.

1. Actual Congressional hearings which encompass agents or actors can be complicated and often very dynamic. Thus, this study was limited by the narrative text provided as a written record of the hearings, which did not include the actual visual presentation that may have been provided by these agents and/or actors.
2. The study is also limited by the reliance on US Government Printing Office to provide an accurate, written record of the hearings.
3. There were only a limited number of hearings available for research funding policies for breast cancer.
4. Also, four assumptions were made:
    - the Congressional hearings used in the study were inclusive of breast cancer policy hearings;
    - Congress invited all of the appropriate parties to testify at the hearings;
    - the ACF served as a good framework for this type of analysis;
    - and that the variables chosen for study will be adequate.

Though two independent coders were used to validate the coding sheet, this study did have the potential limitations described above.

Significance and Implications for Research and Policy

This research study provides two different levels of significance and implications for future research: theoretical and practical. The theoretical significance of this work lies with utilizing the ACF and Congressional hearings to determine the role of environmental carcinogens on breast cancer causation. Though the ACF has been utilized to analyze the policy process for other environmental policies, prior to this work it had not been used to analyze the role of environmental causation of a disease. This work also contributed to the current body of literature for the use of the ACF and provided an example of how Congressional hearings may be used to show power dynamics during the policy process.

The future research implications from the theoretical significance of this work include: this work provides a specific approach on how to utilize the ACF to study policy processes for funding of research and public health activities and it provides a mechanism for integrating social theory and the environmental public health policy process to better understand the role of power and economics during policy development.

The practical significance of this work is that it addressed the funding disparities for breast cancer and to shed light on how and why policies are determined and maintained. This research study can be expanded to in the future to include other cancers and the associated research activities to determine if there are research funding disparities. This research design can be replicated for other disease as well by identifying the major advocacy coalitions involved and conducting a content analysis of the appropriate policy documents.

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